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YOGA INTERVENTION FOR ADOLESCENT FEMALES WITH JUVENILE IDIOPATHIC ARTHRITIS

by

AMANDA BETH FEINSTEIN

Under the Direction of Lindsey L. Cohen and Akihiko Masuda

ABSTRACT

Juvenile idiopathic arthritis (JIA) is a chronic rheumatic disease associated with pain, stiffness and increased psychosocial burden. The purpose of this study was to investigate through an ABAB single-case design the impact of a yoga intervention on pain and morning stiffness in adolescent females with JIA. A secondary aim was to assess the impact of this intervention on self-efficacy, mindfulness, and health-related quality of life (HRQOL). Two adolescents with JIA participated in three yoga groups and daily home yoga practice with a DVD. Participants engaged in daily self-monitoring of pain and stiffness and completed questionnaires assessing psychosocial functioning at pre- and post-intervention. A three-month follow-up on primary and secondary measures was conducted. Primary outcomes were evaluated using visual inspection

and the conservative dual criterion (CDC) method. Results suggested that for one participant, there were no overall systematic changes in pain or stiffness as a result of the intervention; however, trends toward changes in pain were present during the final phases of the study. For the second participant, systematic changes were observed across most but not all phases for morning stiffness, whereas results for pain were less consistent. Modest changes were revealed on secondary outcome measures; however, not consistently in the direction of hypotheses. Lack of stable baseline data for both participants was a significant limitation of the study and is discussed. More research is needed to determine if the yoga intervention utilized in this study is an effective method for reducing pain and stiffness and enhancing psychosocial functioning in adolescent girls with JIA.

INDEX WORDS: Juvenile idiopathic arthritis, Yoga, Pain, Quality of life, Single-case design, Adolescents

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IDIOPATHIC ARTHRITIS

by

AMANDA BETH FEINSTEIN

Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

in the College of Arts and Sciences

Georgia State University

2014

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2014

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DEDICATION

This work is dedicated to the living and loving memory of Mukunda Tom Stiles- yogi, physical therapist, teacher, and guide- who passed on February 18th 2014. Thank you for your offering of a gentle yoga practice that eases the pain of the body and the heart. With great respect and love.

This research is also dedicated to my mentor, friend, and teacher Dr. Eric Cassell. Thank you for teaching me so much about suffering, the relief of suffering, and the healing of body, mind, and soul. Your teachings will continue to influence my work and my life for years to come.

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INTRODUCTION

Overview of Juvenile Idiopathic Arthritis

Juvenile Idiopathic Arthritis (JIA) is a chronic inflammatory autoimmune disease of unknown etiology with onset occurring at the age of 16 or earlier (Cassidy, 2004). It is one of the most common rheumatic diseases of childhood, and the fifth most common chronic disease of childhood, affecting nearly 300,000 individuals under the age of 17 (The Arthritis Foundation, 2007; Cassidy et al., 2005; Helmick et al., 2008; Sacks, Helmick, Luo, Ilowite, & Bowyer, 2007). Formerly known as juvenile rheumatoid arthritis (JRA) or juvenile chronic arthritis (JCA), JIA is the current terminology used to describe the following seven categories of juvenile arthritis: polyarthritis rheumatoid factor (RF) negative, polyarthritis RF positive, systemic, oligoarticular, psoriatic arthritis, enthesitis-related arthritis, and undifferentiated arthritis (Petty et al., 2004). Primary manifestations of JIA, including joint pain, inflammation, stiffness, and fatigue, are expressed across JIA subtypes, with the exception of systemic JIA in which the clinical manifestations include fever, rash, and internal organ involvement, typically accompanied by joint symptoms (Petty & Cassidy, 2005).

JIA disproportionately affects females except in systemic disease in which males and females are equally impacted, and in enthesitis-related disease, which more frequently impacts males (Ravelli & Martini, 2007). Age of onset also varies, ranging from early onset (prior to age six), as seen in the oligoarticular subtype, to adolescent onset, seen in a subset of those with polyarticular RF positive disease (Ravelli & Martini, 2007). Epidemiological studies reveal that children of European ancestry are at increased risk of developing all subtypes of JIA except for RF positive polyarticular disease and systemic onset, in which children of African, Indian, and Native North American descent are at higher risk (Saurenmann et al., 2007). Characteristics such as young age of onset, RF positive disease, and systemic onset disease have demonstrated

relations to poorer functional outcomes (Flato et al., 2002; Packham & Hall, 2002). The causes of JIA are largely unknown, but there appears to be a complex genetic component involving an autoimmune response (Cassidy & Petty, 2005), in which the immune system attacks the individual's joints, cartilage, and tissue surrounding the joints. There is no single diagnostic test to confirm the presence of JIA, but it can be diagnosed clinically through the evaluation of a core set of outcomes, including disease activity, parent/patient assessment of overall well-being, functional ability, number of joints with active arthritis, number of joints with limited range of motion, and erythrocyte sedimentation rate (ESR), a lab value helpful in monitoring the effects of inflammation and response to medication (Giannini et al., 1997).

Symptoms of Juvenile Idiopathic Arthritis

One of the principal symptoms of JIA is pain which is commonly experienced daily. Pain fluctuates within and across individuals with JIA, and data suggest that typical pain is in the mild to moderate range with one quarter of children experiencing severe pain (Anthony & Schanberg, 2003; Schanberg, Gill, Anthony, Yow, & Rochon, 2005; Schanberg, Lefebvre, Keefe, Kredich, & Gil, 1997; Stinson et al., 2008; Tupper, Rosenberg, Pahwa, & Stinson, 2013). An electronic diary study, which assessed daily pain three times per day over the course of a one month period, found that across JIA subtypes, patients endorsed pain level as being “high” (i.e., pain intensity score greater than 40 on 100mm visual analogues scale) in 31% of all entries (Bromberg, Connelly, Anthony, Gil, & Schanberg, 2014). Children often describe arthritis pain qualitatively as “aching,” “sharp,” “burning,” and “uncomfortable,” and it is generally experienced upon active or passive motion of the joint rather than at rest (Beales, Keen, & Lennox Holt, 1983; Varni, Thomson, & Hanson, 1987). In the same electronic diary study cited above, Bromberg et al. (2014) found that patients reported pain an average of 72% of days over the one month

period, and similar rates of pain reporting have been found specifically in those with polyarticular disease (Schanberg et al., 2005).

Joint inflammation and swelling are other core characteristics of JIA, which may cause limitations in range of motion of the joint and interfere with daily living. Joint pain and inflammation are related to morning stiffness, a symptom that is described as a temporary achiness experienced upon waking from sleep, which is often behaviorally exhibited as retardation in motion or activity. Considered to be an important determinant of health status in youth with JIA, morning stiffness is a common symptom and can range from a slight stiffening of joints to prolonged morning stiffness causing more extended impairments in daily mobility (Scott, 1960; Selvaag, Flatø, Lien, Sørskaar, Vinje, & Førre, 2003). Duration and severity of morning stiffness may vary within and across patient subgroups. In youth with polyarticular disease, research examining daily stiffness over a two-month period revealed that participants report morning stiffness an average of 74.1% of days and rate average stiffness as 30.6 ($SD = 22.3$) on a 0-100 visual analogue scale, with higher scores indicating greater stiffness (Schanberg et al., 2005). Although little research has documented the impact of morning stiffness on physical and psychosocial functioning, a recent study of children and adolescents with JIA found that stiffness intensity at the time of measurement predicted functional limitations at that time (Bromberg et al., 2014).

Large joints are most frequently involved (e.g., knees and hips), although small joints such as those of the hands and feet are also commonly impacted (Cassidy et al., 2005). Upper extremities that are most affected are elbows, wrists, and shoulders. Across JIA subtypes, the most common joints of the lower body to be affected are the knees, hips, and ankles, as well as the joints in the feet (Cassidy & Petty, 2005). Loss of full extension of the joint can occur as a

result of swelling and stiffness related to JIA (Cassidy & Petty, 2005) and has been found to be a strong indicator of functional disability (Bekkering et al., 2001). Disability is a problematic manifestation of JIA and predictors of disability include female sex, symmetric arthritis, hip joint involvement, long duration of elevated ESR, and positive RF (Flato et al., 2002).

Exacerbations of disease symptoms, including increased pain, inflammation, and prolonged morning stiffness, are often referred to as “flares” in disease activity and can be problematic for youth with JIA. For example, despite treatment, flare rates as high as 20% over the course of a two-month period have been reported in school-age children with polyarticular disease (Schanberg, Anthony, Gil, & Maurin, 2003). Fluctuations in disease activity and pain might be linked to a number of factors including psychosocial aspects of functioning (Schanberg et al., 2005)

Psychosocial Functioning of Youth with Juvenile Idiopathic Arthritis

Symptoms of chronic illness have been linked to decrements in social and emotional functioning, whereas a variety of psychosocial factors have been linked to better functioning in chronic illness populations generally, and those with JIA. For example, pain across pediatric populations has been linked to functional disability (Gauntlett-Gilbert & Eccleston, 2007; Logan & Scharff, 2005). Specifically among youth with JIA, pain has been found to predict poorer overall psychological adjustment (Billings, Moos, Miller, & Gottlieb, 1987; Sandstrom & Schanberg, 2004), diminished quality of life (QOL; April, Feldman, Platt, & Duffy, 2006), and health-related quality of life (HRQOL; Sawyer et al., 2005; Shaw, Southwood, Duffy, & McDonagh, 2006). Socially, greater morning stiffness is related to fewer social engagements and reduced school attendance in children and adolescents with JIA (Schanberg et al., 2005). Patients

with greater subjective reports of disability report longer duration of morning stiffness (Dempster, Porepa, Young, & Feldman, 2001).

Self-efficacy has been linked to positive functioning in both youth and adults with arthritis (Barlow, Shaw, & Wright, 2001; Smarr et al., 1997). Self-efficacy (SE) is defined as “beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments” (Bandura, 1997, p. 3). With regard to chronic illness generally, SE may be described as one’s perceived ability to manage aspects of one’s illness and specifically, the perceived ability to manage arthritis sequelae in the context of JIA (Barlow, et al, 2001). SE is considered to be one of the most critical psychosocial variables in understanding functional disability and pain in adult RA populations (Somers et al., 2010). Specifically, increases in SE associated with participation in self-management interventions predicted improvements in functional status, pain, and depressive symptoms in adults with RA (Smarr et al., 1997). Despite the dearth of literature exploring this construct in the JIA population, SE has emerged as an important variable predictive of positive outcomes in other pediatric chronic illness populations (e.g., asthma, cystic fibrosis, sickle cell disease, cancer, diabetes) (Boardway, Delamater, Tomakowsky, & Gutai, 1993; Miles, Sawyer, & Kennedy, 1995; Reeb & Bush, 1996; Thompson, Gustafson, Gile, Godfrey, & Murphy, 1998). Given the importance of SE in the adult arthritis and pediatric chronic illness literature, SE is a worthy construct to examine in the JIA population, specifically in the context of the implementation of self-management interventions.

Mindfulness is another variable that has been linked to psychological well-being in pediatric and adult populations (Brown & Ryan, 2003; Greco, Baer, & Smith, 2011; McCracken, Gauntlett-Gilbert, & Vowels, 2007). Mindfulness may be defined as enhanced attention and awareness of present moment experience, with a focus on openly observing internal and external

stimuli (Brown & Ryan, 2003). Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1990), Acceptance and Commitment Therapy (ACT; Dahl, Wilson, Luciano, & Hayes, 2005), and Contextual Cognitive Behavior Therapy (CCBT; McCracken, 2005) utilize mindfulness principles and/or exercises with people with chronic pain. These interventions focus on fostering open awareness of the present moment experience, including unpleasant internal experiences such as painful sensations, thoughts, and emotions, without trying to avoid, change, or reduce them.

Although mindfulness has not been explicitly explored in youth with JIA, pertinent literature suggests its relevance to the psychological adjustment of this population (Semple, Lee, Rosa, & Miller, 2010). For example, acceptance – defined as mindfully embracing difficult experiences – of pain has been found to be related to higher overall QOL (Feinstein et al., 2011). Psychological flexibility, which may be defined as one's ability to contact the present moment more fully (Hayes, Luoma, Bond, Masuda, & Lillis, 2006), has been shown to be related to higher overall QOL, lower levels of anxiety, and higher HRQOL in adolescents with JIA (Feinstein, et al., 2011). The nascent yet growing child and adolescent literature suggests that mindfulness may reflect greater functioning and overall well-being (Semple, Lee, Rosa, & Miller, 2010).

HRQOL may be defined as the patient's own views of their health as assessed across physical, psychological, and social domains (Feldman, Grundland, McCullough, & Wright, 2000; Gong, Young, Dempster, Porepa, & Feldman, 2007). Among research with samples of youth with JIA, HRQOL has been found to be negatively related to various aspects of functioning including pain, disability, depression, frustration, and disease activity (Sawyer et al., 2004; Shaw et al., 2006). Specifically, adolescents with JIA have reported that their most salient

impairments in HRQOL stem from difficulties with gross motor functioning (e.g., kneeling for several minutes, running two blocks) and systemic problems (e.g., disease characteristics such as stiffness, joint tenderness/swelling) (Shaw, Southwood, Duffy, & McDonagh et al. 2006). In contrast, some psychological variables such as psychological flexibility have been associated with higher reports of HRQOL in adolescents with JIA (Feinstein, et al., 2011). Thus, interventions that address the combination of disease characteristics (e.g., pain, stiffness), physical functioning, and psychological functioning may be useful to increase HRQOL in this population.

Treatment of Juvenile Idiopathic Arthritis

Although multidisciplinary treatment utilizing pharmacological, physical, and psychosocial strategies is the ideal and recommended treatment for JIA, the majority of treatments focus on disease modifying medications (Cassidy & Petty, 2005). These medications generally aim to mitigate symptoms such as joint inflammation, pain, and stiffness, and halting the progression of the disease. Medical treatment of JIA has improved in the past 10-15 years with the advent of new disease-modifying anti-rheumatic drugs and biologic therapy, and the expansion of these agents used to treat JIA has induced remission in many patients. However, despite these treatments, some patients, particularly those with polyarticular and systemic-onset subtype, continue to have active symptoms, which are accompanied by lower physical and psychological functioning (Hayward & Wallace, 2009; Wallace, Huang, Bandeira, Ravelli, & Giannini, 2005). Specifically, recent research suggests that children and adolescents with JIA continue to endorse levels of pain, stiffness, and fatigue comparable to those in the pre-biologic era (Bromberg et al., 2014).

Physical and occupational therapies can be utilized to help maintain and improve range of motion, muscle strength, and skills for daily living in youth with JIA (Hafner, Truckenbrodt, & Spamer, 1998). Similarly, exercise programs have been demonstrated to positively impact the health status of youth with JIA (Klepper, 1999; Takken, van der Net, & Helders, 2001). Despite prior assumptions that exercise may exacerbate disease activity in both adults with RA as well as youth with JIA, individually tailored exercise programs are now considered safe and may be an essential part of multidisciplinary treatment (Klepper, 1999; for a review, see Klepper, 2003). One study reported that an 8-week, low impact, weight-bearing, conditioning program designed for youth with JIA resulted in significant reductions in joint count and articular severity index (i.e., assessment combining limitation of motion, swelling, tenderness, and pain on passive motion indices), without any significant exacerbations in disease activity (Klepper, 1999). However, Klepper (1999; 2003) notes that little research has been conducted exploring the most effective, safe, and fun modes of exercise for youth with JIA.

Youth with JIA have also been shown to benefit from psychologically-oriented interventions. The extant literature includes cognitive behavioral interventions for pain management, which have instructed patients in a broad range of psychological and behavioral methods, such as guided imagery, progressive relaxation, and operant pain management techniques (Lavigne, Ross, Berry, Hayford, & Pachman, 1992; Walco, Varni, & Ilowite, 1992). Lavigne et al. (1992) examined the utility of a cognitive behavioral treatment package for children with moderate to severe JRA pain (ages 6-17, $N = 8$), which taught children progressive muscle relaxation, enhancement of relaxation through use of electromyogram biofeedback, and autogenic exercises (e.g., self-statements) with relaxing imagery. Parents were provided with psycho-education about operant pain management techniques, and practice of behavioral

management techniques and relaxation exercises were encouraged at home. Using a multiple-baseline design, results indicated modest reductions in self-reported and parent-reported pain from pre-treatment to 6-month follow-up.

Walco et al. (1992) tested an 8-session individualized cognitive behavioral pain management intervention that was comprised of self-regulatory strategies including progressive muscle relaxation, meditative breathing, and guided imagery. Participants ($N = 13$) were provided with an audiotape of the techniques in order to practice and implement strategies at home and parents also met with a therapist to learn behavioral management strategies related to their child's chronic pain. Results demonstrated statistically and clinically significant reductions in pain intensity from pre- to post- treatment, and improvements in adaptive functioning at 6- and 12-month follow-ups.

Other psychosocial interventions include a retreat for children with arthritis and their families to address problems with pain and behavior (Hagglund et al., 1996) and summer camps for children with rheumatic diseases intended to bolster self-esteem (Stefl, Shear, & Levnison, 1989). Compliance trials to improve medication adherence (Rapoff, Lindsley, & Christophersen, 1984; Rapoff, Purviance, & Lindsley, 1988) have also been explored, as well as interventions designed specifically for adolescents with JIA. One intervention for adolescents addressed transitional care issues including medical, psychological, and educational/vocational needs of adolescents as they move from child to adult-centered health care (McDonagh, Southwood, & Shaw, 2006). Another utilized a narrative form of therapy called the Self-Confrontation Method to aide teenagers in integrating their experience with chronic arthritis into their personal narrative and identity formation (Fuchs, et al., 2013). Only one other intervention (i.e., internet-based self-

management program) has been reported in the literature that specifically targeted adolescents (Stinson et al., 2010).

In summary, although evidence is limited, youth with JIA who participate in interventions teaching self-regulatory strategies to manage pain, including guided imagery, meditative breathing, and progressive muscle relaxation (Lavigne et al., 1992; Walco et al., 1992) seem to experience improvements in pain. According to JIA experts, an optimal treatment approach for JIA utilizes multidisciplinary care combining pharmacology, physical and psychosocial approaches, with the goals of fostering psychological and social development and decreasing pain and other symptoms (Cassidy & Petty, 2005). An ideal adjunctive therapy for youth with JIA should target the physical and structural symptoms of pain and joint stiffness and aim to improve psychological factors related to greater well-being, such as self-efficacy and mindfulness. Yoga might fulfill these criteria.

Overview of Yoga and its Application to Juvenile Arthritis

Yoga is an ancient spiritual tradition and practice originating from India that seeks to bring the body, mind, and spirit into harmony and balance. Yoga has a number of different components (e.g., postures, breathing, meditation), which are practiced in numerous methods or styles (Stiles, 2000). Hatha yoga, the most prevalent method in Western societies, emphasizes physical postures (asanas) and breathing exercises (pranayama) that are used to promote physical health, relaxation, and well-being.

Today, yoga is understood and practiced largely as a system of physical exercise, and the mind-body relationship central to traditional yoga practice is often ignored. From a traditional understanding of yoga, asanas are viewed as tools to increase one's awareness and consciousness (Saraswati, 2008). Awareness may be understood as heightened focus on sensations in the body

including physical movement, posture, breathing, combined with the observation of thoughts, feelings, or emotions that may arise during yoga practice. From this perspective, body and mind are viewed as interrelated and integrated, and asana practice is intended to synchronize mind and body.

Traditional conceptions of yoga are beginning to be explained through modern conceptual models purporting that physiological/structural, psychological, and spiritual facets interrelate to one another, (Evans, Tsao, Sternlieb, & Zeltzer, 2009). Taken together, these components may be responsible, as a whole, for comprising the health benefits of yoga. For example, physiologic/structural benefits may include changes in the musculoskeletal system such as increasing range of motion in the joints and relaxing muscles (Evans et al., 2009). Additionally, in alignment with this model, psychological constructs such as self-efficacy and mindfulness, may also be influenced by yoga practice. Researchers (Evans et al., 2009) speculate that as yoga directly impacts structural, psychological, and spiritual dimensions of a person that, in turn, aspects of functioning such as pain and quality of life may improve. The integration of these components is what may differentiate yoga from simply an exercise routine or cognitive behavioral therapy modality. As such, it has been categorized as a form of Mind and Body Medicine under the larger rubric of complementary and alternative medicine, a set of practices that focus on the interaction between mind, body, brain, and behavior (CAM; National Institutes of Health, 2011)

Yoga has become an increasingly popular intervention to address chronic and persistent pain in adult and pediatric populations (Wren, Wright, Carson, & Keefe, 2011), including chronic arthritis in adults (Evans et al., 2010; Kolasinski et al., 2005). Although yoga interventions have not been used frequently with pediatric populations, a study that examined

preferences among youth with chronic pain syndromes revealed that techniques such as yoga, that enhanced relaxation and increased somatic control, were most popular (Tsao, Meldrum, Kim, Jacob, & Zeltzer, 2007).

Whereas no direct literature examining yoga for JIA exists, yoga has in fact been studied both in other pediatric pain populations, as well as in adults with arthritis. Relevant to the present study, these findings may be informative to developing a yoga intervention for youth with JIA. A review of the clinical applications of yoga in children, including those with pain, suggests that yoga may offer therapeutic benefits to pediatric populations (Birdee et al., 2009). One randomized trial included in that review investigated the beneficial effects of yoga for adolescents, ages 11-18, with irritable bowel syndrome (IBS) (Kuttner et al., 2006). This intervention consisted of a 1-hour in-person yoga instruction session with a teacher certified in Hatha and Iyengar yoga followed by use of a yoga video for daily practice of 10 minutes a day over 4 weeks. Although the style of yoga was not clearly defined, poses were described in detail and selected specifically for the easing quality of the poses on the abdomen and bowel. Results revealed that those in the yoga group reported decreases in functional disability and anxiety, and improvements in gastrointestinal symptoms.

Kuttner et al.'s (2006) study demonstrates how benefits may be obtained from an intervention that only minimally utilized in-person instruction, and relied on brief daily practice with a yoga DVD for the bulk of the practice. Results of this study suggest that home yoga practice with a DVD is a viable and effective way to deliver a yoga intervention to adolescents. The duration of daily practice time was taken into consideration when designing this intervention in order to make it most accessible to adolescent participants and feasible to complete. Despite these considerations, Kuttner et al. (2006) reported that participants described barriers to daily

practice such as other activity commitments. Additionally, Kuttner et al.'s yoga program was tailored to address a specific chronic pain condition (i.e., IBS) using poses thought to specifically impact abdominal discomfort. Despite tailoring, study participants stated that the intervention would have been more helpful if they had more yoga poses to choose from and could choose them based on how they were feeling, suggesting participants' desires for even more specificity and options related to their pain condition.

Regarding the use of yoga to manage arthritis in adults, most studies have utilized Iyengar yoga, a style of yoga in which precision, alignment, and the use of props are common, and it is suggested that this style can be performed by anyone (Iyengar, 1966). Garfinkel et al. (1994) utilized an Iyengar-based protocol for adults with osteoarthritis of the hands and found that the yoga group, compared to the control group, experienced significant improvements in pain and grip strength. A pilot study investigating the use of Iyengar yoga for osteoarthritis of the knees demonstrated improvement in pain disability and affect (Kolasinski et al., 2005).

Another study consisted of a 12-session wait-list control yoga program for 47 adult patients with rheumatoid arthritis (RA), a disease more similar to JIA than osteoarthritis, and utilized both a group format in which participants met for 1 hour twice a week for 6 weeks combined with a home practice (Badsha, Chhabra, Leibman, Mofti, & Kong, 2009). This protocol, implemented in the United Arab Emirates, utilized a style of yoga (Vishwas-Raj yoga) that focuses on a combination of meditation, stretching, strengthening, and deep breathing. Poses were conducted in a variety of postures including from a chair, lying down, and sitting. Results of this intervention revealed improvements in tender and swollen joint count, functioning, and disease activity scores and, additionally, reduction and discontinuation of medication was seen in

seven participants in the active group, while no participants in the control group reduced or discontinued medication.

A pilot study targeting a young adult subgroup with RA demonstrated benefits of yoga on various facets of participants' functioning (Evans et al., 2010). This program utilized a therapeutic sequence from the Iyengar tradition, which emphasized alignment and the use of props to decrease the likelihood of causing stress to the joints (Iyengar, 1966). Five 24- to 31-year-olds with RA participated in the 6-week program, consisting of two 1.5-hour sessions of yoga per week. Participation resulted in improvements in pain, disability, and components of mental health, including depression, vitality, and self-efficacy.

Although the yoga protocol utilized in this study (Evans et al., 2010) was described as being specifically suited for people with RA, certain traditional poses (e.g., inversions, triangle, modified downward dog), though modified, may still be challenging to individuals with significant loss of range of motion in certain joints (e.g., wrists, shoulders, hips). Additionally, although the yoga program was demonstrated to be safe in the context in which it was applied, certain poses utilized in this program may not be safely recommended for patients to practice on their own, making regular daily practice less accessible. In terms of qualitative data ascertained from participants, it was noted that when the intervention ended, and participants stopped practicing yoga, they no longer experienced improvements in their symptoms. Thus, it would be prudent to consider adding a home yoga component in future studies to provide participants with tools for potentially maintaining their gains following the termination of the intervention.

Current Study

Based on prior studies (e.g., Evans et al., 2010; Kuttner et al., 2006), a yoga intervention for people with chronic pain should integrate in-person instruction with home practice in a safe

and accessible format that provides diversity and selection of postures. The method of combining in-person instructions with a home-based practice accompanied by DVD is an innovative way to make yoga more accessible to adolescents. Given growing desires for independence during adolescence, providing a strategy that youth can largely complete on their own, may assist them in gaining confidence to self-manage aspects of their disease.

Although Iyengar yoga is a style often selected for people with chronic pain conditions based on its adaptability, modifications needed for arthritis patients with limitations or structural changes in their joints, may not be capable of safely and comfortably replicating postures at home and may rely on regular in-person instruction to attain benefits.. Additionally, as the Evans et al. (2010) study revealed, after yoga classes terminated, results might not be maintained. Thus, understanding the impact of daily yoga on daily functioning, using a format that is tailored to patients with JIA, appears necessary.

In terms of the intervention needs of adolescents with JIA, a multidisciplinary self-management program that addresses the physical/structural aspects of JIA and promotes well-being related to psychological/psychosocial factors is needed. Consistent with these criteria, Stinson et al. (2008) found that adolescents with JIA explicitly desired greater availability and access to comprehensive self-management interventions. In addition to learning self-management techniques, the adolescents in Stinson et al.'s (2008) study reported wanting support from peers. Lastly, no interventions exist that specifically target pain and morning stiffness in adolescents with JIA.

Primary Aims and Hypotheses

The purpose of the current study was to use a single-case reversal ABAB design to assess the impact of a yoga intervention on pain intensity, morning stiffness intensity, and morning

stiffness duration in adolescent females with JIA. It was hypothesized that participants would report lower pain and morning stiffness when practicing yoga than when not practicing yoga. A secondary aim was to examine whether the adolescents' self-efficacy, mindfulness, and HRQOL improved over the course of the study. Lastly, pain, morning stiffness, self-efficacy, mindfulness, and HRQOL were assessed at 3-month follow-up to determine whether treatment gains were maintained.

METHOD

Participants

Inclusion criteria consisted of the following: 1) patient was between 12 and 18 years of age; 2) diagnosis of JIA by a pediatric rheumatologist; 3) average self-reported pain score of 3 or higher based on numerical rating scale from 0 (*no pain*) to 10 (*worst pain you can imagine*) or average minimum of 30 minutes duration of self-reported morning stiffness; 4) stable disease¹ for a minimum of three months, as defined by no significant changes in treatment according to physician; 5) minimum of three joints with active arthritis; and 6) daily access to a DVD player or computer on which to watch the yoga DVD. Exclusion criteria consisted of those patients who were currently enrolled in other yoga classes, in other exercise programs, or in psychotherapy targeting pain management or coping with JIA. Additionally, patients who did not speak English, who were pregnant, or who were cognitively impaired were excluded from participation. Those who required immediate medical care or had a history of severe mental illness (i.e., psychotic disorders) were also excluded from the study due to safety issues. If changes in medication occurred after the start of the intervention, participants were allowed to remain enrolled in the study, and the date and nature of the medication change was collected. Additionally, participants were asked to inform the research team if and when they began a yoga, exercise, or pain management program during the course of the study.

Participating rheumatologists referred 22 patients who met the age and diagnosis inclusion criteria. Eleven of these patients met full study criteria and chose to enroll in the study. Numerous patients who did not meet criteria reported disappointment about not being able to enroll in the study and described interest in future yoga programs for JIA. See Figure 1 for a flow

¹ The nature and course of JIA is often marked by instability and fluctuations in disease activity, pain, and stiffness. Thus, given those parameters, the pediatric rheumatologists used clinical judgment to recommend patients for participation.

chart of participant enrollment. Two participants completed the full intervention including all three yoga sessions as well as consistently engaged in home yoga practice; thus, data from these two participants were used in the final analyses.

Participant 1, who has been given the pseudonym “Jen” for the purposes of the study, was a 15-year-old, 9th-grade, Caucasian female with polyarticular RF negative JIA with a disease onset at age 12. Participant 2, given the pseudonym “Nina” was a 17-year-old, 12th-grade female of Asian descent with polyarticular RF positive disease. Her disease onset was at age 14.

Setting

Patients who met inclusion criteria were greeted and consented by the primary investigator at the outpatient clinic at Emory Children’s Center Division of Pediatric Rheumatology. All yoga group sessions took place on weekends at the Emory Children’s Center in a carpeted semi-private space.

Design

An ABAB reversal single-case design was used, which combines an applied clinical focus with scientific rigor, yielding high internal validity (Kratochwill et al., 2010; Cohen, Feinstein, Masuda, & Vowles, 2014). Specifically, single-case designs are recommended when exploring functional relations among variables (i.e., causal relation between independent and dependent variables) and are well suited for testing novel interventions (Cohen et al., 2014; Drotar, La Greca, Lemanek, & Kazak, 1995; Kratochwill, Hitchcock, Horner et al., 2010; Rapoff & Stark, 2008). The ABAB design involves gathering baseline data (A_1), instating a treatment or intervention (B_1), removing or withdrawing the intervention (A_2), and then reinstating the intervention (B_2). In the current study, daily self-report of pain and stiffness were the primary outcome variables. If after establishing a baseline (A_1), pain and stiffness levels decrease during

the first yoga treatment phase (B_1), revert to baseline levels when treatment is withdrawn (A_2), and then again decrease during the second yoga phase (B_2), evidence would exist for reductions in pain and stiffness being a function of the yoga intervention.

A minimum of one participant is needed for an ABAB design because the participant provides its own control for comparison; however, having several participants can assist in demonstrating replication of effects (Kazdin, 1982; Kratochwill et al., 2010). Outcome variables in single-case designs must be measured repeatedly during each phase. In accordance with standard guidelines (Kratochwill et al., 2010), reversal designs must have a minimum of four phases per participant (e.g., ABAB) and a minimum of five data points (i.e., data reported at least 5 days per participant) of target behavior per phase in order to interpret the effects of treatment (Kazdin, 2011; Kratochwill, et al., 2010). Additionally, the intervention must be systematically manipulated by the researcher to meet standards (Kratochwill et al., 2010).

Treatment effects are often interpreted in terms of the following criteria: level, trend, variability, consistency, and latency (Cohen et al., 2014; Kazdin, 2011; Kratochwill et al., 2010). Level is considered to be the mean score of the data within a particular phase. Trend refers to the slope and the direction (i.e., increasing, decreasing) of the data within a phase. Variability is understood by comparing the range of the data points within and across phases. Consistency refers to the examination of patterns of data when comparing phases. Latency describes the immediacy or delay of changes in data observed when a phase is introduced.

In an ideal ABAB design, initiation of the active treatment is typically determined based on stability of baseline data (Kazdin, 1982). However, given the practical demands of conducting the present study, the dates of group yoga sessions (i.e., start of B_1) were pre-determined and scheduled. The principal investigator and the participants met during the consenting process, and

instructions were given for a date to begin daily self-monitoring of pain and morning stiffness. Jen's baseline data (A_1) consisted of 26 data points, whereas Nina's baseline (A_1) was comprised of 16 data points. Jen's subsequent phases, B_1 , A_2 , and B_2 , were precisely 14 days each, as instructed. Nina's first yoga phase (B_1) was 15 days, her reversal phase (A_2) was 13 days, and her final yoga phase (B_2) was 13 days. Phase lengths for Nina varied according to both when the principal investigator was able to reach Nina by phone or email, and when Nina initiated the change in accordance with instructions. The extended baselines and relatively long yoga phases of 2 weeks were selected to balance the aim to obtain stable data with the recognition that JIA is characterized by fluctuations in pain and stiffness.

Measures

Demographics. A demographic questionnaire was administered to caregivers. Questions assessed background information about the adolescent (e.g., age, gender, ethnicity, and health status) and also about the caregiver (e.g., relation to adolescent, gender, age, ethnicity, race, education, occupation, family income, health status). Adolescents were also asked to answer several demographic questions (age, grade in school, disease subtype, JIA onset and duration).

Pain Intensity. Pain intensity was measured via an 11-point numerical rating scale (NRS-11). The scale ranges from 0 (*no pain*) to 10 (*worst pain you can imagine*). The NRS-11 is said to be the most commonly used scale in pediatric clinical settings with children over the age of 8 (von Baeyer, 2006). Miro, Castarlenas, and Huguet (2009) have demonstrated adequate validity for assessing pain intensity in both clinical and non-clinical samples of children as young as six and eight, respectively. Additionally, in adult populations, a reduction of approximately two points on the NRS-11 indicates clinically important changes in pain (Farrar, Young, LaMoreaux, Werth, & Poole, 2001). Pain was measured with this tool on a daily basis

throughout the duration of the study through either a paper diary or online survey. Participants were instructed to record their pain intensity scores upon awakening and 30 minutes after awakening. Pain was also measured at each yoga group and again daily at 3-month follow-up.

Morning Stiffness. Participants reported on the intensity of their morning stiffness using an 11-point numerical rating scale, anchored by 0 (*not stiff at all*) and 10 (*very stiff*). They were instructed to record their stiffness intensity upon awakening and 30 minutes later. Additionally, duration of morning stiffness, operationalized as the amount of time in minutes or hours that the adolescent experiences joint achiness and stiffness in the mornings, was measured via self-report. Participants recorded stiffness duration at a later point in the day as stiffness may last up to a few hours. Daily stiffness intensity and duration reports were also collected at 3-month follow-up.

Yoga Practice. Participants reported on whether or not they engaged in yoga each day by responding “yes” or “no” to a simple stem question (i.e., Did you practice yoga today?). If they endorsed yoga practice, they also indicated which track(s) from the yoga DVD they practiced by selecting from the listed answer choices (e.g., “1. Intro;” “2. Breathing;” “3. Ankles, Knees, Hips”). This was begun at the start of the first yoga phase, continued through the duration of the intervention, and was then reported again at 3-month follow-up for two weeks.

Self-efficacy. Self-efficacy was measured by the Children’s Arthritis Self-Efficacy Scale (CASE; Barlow, Shaw, & Wright, 2001), an 11-item Likert format scale specifically designed for school-aged children and adolescents with JIA that assesses perceived self-efficacy as related to three arthritis-specific content areas which comprise the subscales: activities, symptom management, and emotions. Questions are specific to perceived control over arthritis (e.g., “I can find ways to control the stiffness of arthritis” “I can control my arthritis at school”). The Likert choices range from 1 (*not at all sure*) to 5 (*very sure*). The CASE is scored by calculating

subscale totals that range from 3 to 20, with total scores ranging from 11 to 55. Higher scores indicate greater self-efficacy. The CASE has been validated in samples aged 7-17 years.

Coefficient alphas for the 3 subscales were reported as follows: activity, $\alpha = 0.90$; symptoms, $\alpha = 0.87$; and emotions, $\alpha = 0.85$ (Vuorimaa, Honkanen, Konttinen, Komulainen, & Santavirta, 2007). Adequate face, content, construct, and criterion validity have all been established (Barlow et al., 2001). Self-efficacy was assessed at the first in-person yoga session following the completion of the baseline phase (A_1), at the final in-person yoga session (completion of B_2), and at 3-month follow-up.

Mindfulness. The Mindful Attention Awareness Scale- Adolescent form (MAAS-A; Brown, West, Loverich, & Beigel, 2011) is a measure of attention and awareness in daily life activities based on the adult version of the MAAS (Brown & Ryan, 2003). The scale specifically measures individual differences in the frequency of mindlessness (e.g., ‘‘It seems I am ‘running on automatic’ without much awareness of what I’m doing’’), the opposite of the construct of mindfulness, over time because authors suggest that mindless states are more common and accessible to people untrained in mindfulness. The MAAS-A is a 14-item, self-report tool with responses indicated on a 6-point Likert scale ranging from 1 (*almost always*) to 6 (*almost never*), with higher scores reflecting higher trait mindfulness. This scale was validated in a normative sample and an outpatient psychiatric sample, both ages 14-18, demonstrating acceptable internal consistency (normative, $\alpha = 0.85-0.88$; psychiatric, $\alpha = 0.86$). Scores are computed by calculating a total of all items, with higher scores denoting greater mindfulness. The MAAS-A was completed at the first and last in-person yoga sessions and at 3-month follow-up.

Health-related Quality of Life. The Juvenile Arthritis Quality of Life Questionnaire (JAQQ) is a disease-specific questionnaire used for assessing health-related quality of life in

children with arthritis (Duffy, Arensault, Wantabe, Duffy, Paquin, & Strawczynski, 1997). It is a 74-item self-report questionnaire that assesses the following domains: physical functioning, emotional well-being, and general symptoms. The JAQQ is comprised of four subscales including gross motor functioning (17 items), fine motor function (16 items), psychosocial functioning (22 items), and general/systemic symptoms (19 items). The JAQQ also contains a 100mm pain VAS, which was not utilized to maintain consistency in measurement of pain; thus an 11-point numerical rating scale (NRS-11) ranging from 0 to 10 was supplemented.

Participants respond to a stem question, “As a result of arthritis or its treatment, how often have you, over the past 2 weeks, had difficulty with the following activities?” which is answered based on a Likert-type scale ranging from 1 (*none of the time/never*) to 7 (*all of the time*) with an additional response option (0) which indicates that the item does not apply to the child. Across the four subscales, adolescents choose up to five items from each subscale that are the most personally relevant to them, and a mean score is computed from the items selected. The total JAQQ score is calculated to be the mean across all four dimensions. Change in score from one administration to the next can be calculated for both the JAQQ total score and each dimension. Although no specific cut-off points have been established, a higher score indicates poorer HRQOL. This measure was used anecdotally to supplement information about participants’ experiences rather than to determine specific levels of functioning or impairment. Construct validity and sensitivity to change have been demonstrated for the JAQQ. The JAQQ was completed by participants at the first and last in-person yoga sessions and at 3-month follow-up.

Procedures

This study was approved by both Georgia State University and Emory University Institutional Review Boards. The primary investigator was responsible for recruitment and

consenting of all participants. Recruitment was conducted in two phases during November 2011 to March 2012 and June 2012 to October 2012 to enroll patients for two separate waves of the yoga group interventions, which occurred in March 2012 to April 2012 and October 2012 to November 2012. Inclusion and exclusion criteria were explained in more detail prior to consenting the participant and caregiver in order to deem if they meet criteria for inclusion. For those who met criteria, caregivers completed a consent form and the adolescents completed an assent form. Patients were also able to contact the primary investigator via email or telephone to receive more information about the study. Participants received \$10 gift cards each time they completed the questionnaire packets (e.g., first yoga session, last yoga session, and 3-month follow-up).

Adolescents were provided instruction on reporting daily pain and morning stiffness (i.e., intensity and duration) scores on the day of study enrollment. Jen, who participated in the first wave of the intervention, reported scores through a secure online survey. Due to participant difficulty consistently accessing the online survey, paper diaries were used in the second wave when Nina was enrolled. Participants received daily emails from the primary investigator reminding them to record their scores for the day. The primary investigator also called participants 1-2 times per week to collect the pain and stiffness data. During active yoga phases, participants also reported which tracks from the yoga DVD they practiced each day.

Baseline (A_1) consisted of daily self-monitoring for a minimum of 2 weeks. Subsequently, the intervention phase (B_2) began when participants attended the first yoga group. At the first group, participants were provided a DVD to guide in-home yoga practice. A complete description of the yoga program, a modified sequence of The Joint Freeing SeriesTM, and DVD, also based on the Joint Freeing SeriesTM, can be found in Appendix A (Stiles, 2000).

Yoga postures with descriptions are depicted in Table 1. During this first yoga group (see Appendix B), participants were introduced to each other with ice-breaker activities, confidentiality was discussed, and participants were provided with psycho-education about yoga and the specific style being taught in the study. The concept of body awareness was introduced and then participants learned a yoga sequence designed for adolescents with arthritis, including breathing techniques. Jen attended the first group with one other adolescent, whereas Nina's first group contained three additional adolescents. These additional adolescents either withdrew from the study or did not complete full study procedures and therefore were not included in analyses. The first session lasted approximately three hours and light refreshments were provided after the yoga portion of the class was complete. At the end of the yoga session, participants were given a copy of a DVD, which reviewed the yoga sequence they learned during the yoga group. The participants were instructed to practice with the DVD every morning. Specifically, they were asked to do *at least* the track focused on breathing plus one other track on the DVD, but it was preferred and recommended that they completed the breathing track, the track focused on back and neck movements, and one other track. In total, participants were expected to practice yoga for an approximate duration of 10-15 minutes daily. They were told to practice after waking and before having breakfast for the next two weeks. Participants were also instructed to keep other morning activities consistent during all phases of the intervention to minimize confounding factors (e.g., if they took morning showers during the baseline phases, they should continue to take morning showers during yoga phases).

At the end of the 2-week yoga phase, the primary investigator called each of the families and instructed the participants to stop practicing daily yoga for the subsequent 2 weeks (A₂).

Participants continued daily reporting of pain and stiffness; however, they were additionally asked if they had practiced yoga as a form of integrity check.

After 2 weeks, the second in-person yoga group occurred (B₂). Both Jen and Nina attended their respective second groups each with one other adolescent. During this session, confidentiality was reviewed and the concept of acceptance was introduced which was interwoven into the yoga practice. Following the discussion, participants were led through the breath work and yoga sequence for approximately one hour. In addition, the instructor answered questions about the yoga sequence and provided appropriate adaptations as necessary. This session was approximately 2.5 hours and light refreshments were served. A more detailed description of the session can be found in Appendix B. At the completion of the second yoga group session (last day of A₂), participants were instructed to practice daily with the DVD again for 2 more weeks. After 2 weeks, participants were invited back to the clinic to attend a final yoga group. This third group was included as way to help participants solidify their yoga skills, collect post-intervention data, and conduct a focus group with participants. Jen attended this group alone, as no other adolescents arrived that day. Nina's final group was attended by one other adolescent. Following approximately 1 hour of yoga practice, the remainder of the session consisted of a focus group, asking participants and their caregivers to describe their experience participating in the study. The final group lasted approximately 2.5 hours and refreshments were provided. Following the completion of the third yoga group, participants no longer completed daily assessments.

Follow-up. Three months after the completion of the intervention, participants were contacted by phone and asked to engage in daily self-monitoring of pain and morning stiffness for two weeks. They were also asked to record daily whether or not they practiced the yoga they

had learned through the study (with or without the DVD), and if so, which tracks they practiced. Jen and her mother completed the three-month follow-up packet during a regularly scheduled clinic visit. Nina requested the packets be sent to the home and both she and her mother completed and returned them. In addition to psychosocial measures, participants and parents were also asked to estimate how many times during the past 3 months the adolescent practiced yoga, motivation for practicing, and barriers that interfered with yoga practice.

Analytic Plan

The data evaluation process traditionally used to assess ABAB reversal designs is that of visual inspection; however, a number of analytical approaches have been introduced in the literature to augment visual inspection (Cohen et al., 2014). To examine pain and stiffness, changes in patterns between the baseline and the intervention phases were evaluated. Specifically, changes in level, trend, variability, consistency, and latency were visually assessed (Cohen, et al, 2014; Kratochwill, et al., 2010). To complement the visual inspection of level and trend, the conservative dual-criterion (CDC) method was employed (Fisher, Kelley, & Lomas, 2003). This method involves generating level and trend criterion lines to aid in the evaluation of changes across phases (Swoboda, Kratochwill, & Levin, 2010). When employing the CDC criteria, a pre-determined number of data points must fall below or above both the mean and trend lines depending on the hypothesized direction of the effect in order to conclude that systematic change has occurred.

In addition to visual inspection and CDC method, percent change scores were also used to explore changes in pain and stiffness intensity. These scores were calculated to describe the average change in pain and stiffness from waking to 30 minutes later compared across phases. Difference scores (e.g., pain/stiffness score at waking minus pain/stiffness score 30 minutes after

waking for each day) were obtained for each day and then averaged within each phase. The mean scores were then compared across phases.

To assess secondary outcome measures including self-efficacy, mindfulness, and health related quality of life, the scores were compared at pre-intervention, post-intervention, and 3-month follow-up. Percent change calculations were also used to evaluate change over time. These secondary data were complimented via anecdotal report from the participants.

RESULTS

Descriptive Data and Adherence to Protocol

Means and standard deviations for pain and stiffness scores across phases are reported in Table 2. Jen engaged in yoga practice 78% of days instructed, but only typically adhered to practicing 1-2 tracks from the DVD. Nina practiced yoga 57% of days, and consistently practiced a minimum of 3 tracks from the DVD. Additionally, Nina reported engaging in the full DVD (i.e., all tracks) 6 times out of the total 16 days she engaged in yoga during the intervention phases. Both participants completed daily diaries again at 3-month follow-up for two weeks, reporting on the same daily measures. Jen recorded pain and stiffness scores 11 out of 14 days, reported practicing yoga 3 of those days, and used one track from the DVD each time she practiced. Nina recorded diary data for all 14 days, reported practicing yoga 4 out of 14 days (on weekends only), and completed the entire DVD each time she practiced.

Treatment Effects Associated with Primary Aims

The two primary aims of this study were to decrease JIA pain and morning stiffness via a yoga intervention. The following describes results based on visual inspection and CDC analysis for (a) pain reported 30 minutes after waking, (b) stiffness reported 30 minutes after waking, and (c) duration of morning stiffness calculated in minutes. The same outcome variables were explored at three-month follow-up through visual inspection alone.

Participant 1: Jen

Pain Intensity. Examining Figure 2 via visual inspection and the CDC method reveals that there was a significant increase in the *level* of pain and change in *trend* from A_1 to B_1 , contrary to hypotheses. No significant changes in pain level were demonstrated comparing B_1 to A_2 via visual inspection or the CDC method; however, there was systematic change in trend from

B₁ to A₂ in opposition to hypotheses using both modalities of evaluation. Consistent with hypotheses, visual inspection suggests a decrease in pain level and significant change in trend from A₂ to B₂, which are supported by the CDC method.

Variability in pain scores decreased throughout Jen's participation in the study. Although the lowest variability is present within the second intervention phase (B₂), variability appears to decrease over time (A₁ to B₂), rather than as a consistent effect of the intervention. Thus, the *consistency* in the pattern of data is weak comparing across yoga phases and non-yoga phases with regard to hypotheses. Small *latency* effects are seen from B₁ to A₂, and from A₂ to B₂; however variability within these phases may preclude conclusions related to latency.

In summary, the only changes in pain level and trend consistent with hypotheses were observed when comparing A₂ to B₂. In fact, there was an increase in level and change in direction opposite of prediction when comparing the baseline (A₁) and first yoga phase (B₁). Examinations of variability, consistency, and latency also do not support systematic changes across the four phases; yet patterns are seen emerging from A₂ to B₂. Thus, one cannot conclude systematic changes in Jen's pain scores as a function of the intervention.

Morning Stiffness Intensity. As can be gleaned from Figure 3, lack of stability in A₁ makes it difficult to visually determine change in stiffness *level* and *trend* comparing A₁ to B₁. CDC method aids in these interpretations suggesting a significant increase in level and change in trend from A₁ to B₁, both contrary to hypotheses. Visually examining B₁ compared to A₂ reveals little change in level, and CDC method reveals similar conclusions with no systematic differences indicated. With regard to trend, variability hinders stronger conclusions from being drawn via visual inspection, but CDC assists in this observation by suggesting a systematic change in trend from B₁ to A₂, opposing hypotheses. Comparing the reversal phase (A₂) with the

final yoga phase (B_2), visual inspection again reveals minimal difference in level and trend, which are both confirmed by no systematic changes indicated by the CDC method.

Great *variability* is present in A_1 and B_1 , yet it decreases over the course of the study. Specifically, phases A_2 and B_2 demonstrate considerably less variability indicating a lack of consistency in patterns of data when examining yoga and non-yoga phases. Small *latency* effects can be seen from B_1 to A_2 , but the variability in phase B_1 hinders conclusions. In summary, evidence across criteria does not support systematic changes in morning stiffness intensity consistent with hypotheses.

Duration of Morning Stiffness. Using Figure 4 to compare *levels* of stiffness duration between phases A_1 and B_1 , a change in level is not apparent via visual inspection, nor is a systematic change revealed via the CDC method. No changes in level of morning stiffness duration are present between B_1 and A_2 , and levels appears stable comparing the reversal phase (A_2) and final yoga phase (B_2) utilizing both visual inspection and the CDC method to evaluate. In terms of *trends*, the variability in A_1 and B_1 makes visual inspection challenging, yet CDC suggests a systematic change in trend between A_1 and B_1 , contrary to hypotheses. Using visual inspection, there is some indication of a change in trend when comparing B_1 to A_2 , with A_2 more clearly stabilizing, but the CDC method rejects systematic change between these phases. Finally, comparing the reversal phase (A_2) and final yoga phase (B_2), no changes in trend are observed via visual inspection nor through the CDC method.

With regard to *variability* of stiffness duration, one can see a clear pattern of decrease through the course of the study (A_1 to B_2) with fewer high extremes in duration of morning stiffness and a decrease in the range that occurs over time; however, as with Jen's other

outcomes, there is greater *consistency* in data patterns between A₂ and B₂ than between A phases and B phases. No notable *latency* effects are present.

To summarize, there are no systematic changes in mean or trend for Jen's morning stiffness duration in the direction of hypotheses according to either visual inspection or the CDC method. Variability in the first two phases (A₁ and B₁) impacts visual conclusions drawn; CDC actually suggests trends opposite of hypotheses. The patterns of variability and consistency do not lend support to hypotheses either. Thus, there is no evidence that Jen's stiffness duration was systematically altered as a result of the intervention.

Three-month follow-up. At 3-month follow-up Jen's pain intensity is lower in level than any of the phases during the intervention and an upward trend is observed. The pattern of data and the range of variability are both most similar to phase A₂. For morning stiffness intensity, Jen's 3-month data are quite variable and exhibit no clear trend. Similarly to pain, stiffness levels are in a lower range at 3-months than any other phase and the pattern is most similar to B₂. Jen's stiffness duration reflects similar patterns of variability, level, and trend to both A₂ and B₂. Although the level of duration of morning stiffness is comparable to that found during the second half of the intervention, it is not discriminately consistent with the yoga phases. In summary, Jen only practiced yoga 3 out of 14 days during the follow-up, yet data reflected patterns of lower pain and stiffness intensity than during any phase of the intervention. Jen's data across pain intensity, morning stiffness intensity, and duration of morning stiffness are consistent with the conclusions found in the ABAB single-case analyses suggesting that there was no change in Jen's primary outcome measures as a result of the intervention.

Participant 2: Nina

Pain Intensity. Examining Figure 5, visual inspection suggests a decrease in *level* of pain scores from baseline (A_1) to the first yoga phase (B_1); however, systematic change was not supported by the CDC method. Comparing these same two phases on *trend*, no systematic change is evident through visual inspection or CDC method. Visually comparing B_1 with the reversal phase (A_2) suggests an increase in pain level when yoga is removed, but this is not supported by the CDC method. Comparing the differences in trend in B_1 (downward trend over time) to A_2 (variability and lack of downward trend), suggests difference between these two phases, which aligns with hypotheses and is supported by the CDC method. Consistent with hypotheses, a decrease in pain level appears most visible from A_2 to B_2 ; yet this change in level only closely approaches the stringent criteria for systematic change set by the CDC method. The variability present in B_2 hinders clearer visual evaluation of changes in trend from A_2 to B_2 , and no systematic change is indicated by the CDC method.

There is a decrease in the *variability* of pain scores during the yoga treatment phases on days in which Nina engaged in yoga compared to the non-yoga phases. *Consistency* in the pattern of data is also present when comparing A phases and B phases, yet detection of a *latency* effect is obscured due to the variability. In summary, Nina's pain data within phases are somewhat variable, including the baseline data, which may limit stronger conclusions from being drawn. Despite lack of stability of the data, pain during both yoga phases appears to be trending toward a decrease; however, data does not meet the stringent criteria via the CDC method.

Morning Stiffness Intensity. Figure 6 assists in comparing Nina's stiffness *levels* and changes in *trend* between A_1 and B_1 . Visual inspection suggests no significant change in level between these phases, aligning with CDC conclusions. With regard to *trend*, variability in the baseline (A_1) impedes clearer visual conclusions and CDC rejects systematic changes in trend

between A_1 and B_1 . Examining B_1 and A_2 via visual inspection reflects lower overall levels of stiffness during the yoga phase (B_1) compared to the reversal phase (A_2); however, the CDC method does not support systematic change, although it approaches the cut-off score. Examining the reversal phase (A_2) indicates a lack of trend, reflecting a notable change via visual inspection from B_1 to A_2 , which is supported by the CDC as a systematic change and aligns with hypotheses. Finally, a change in stiffness level comparing A_2 to B_2 can be clearly observed via visual inspection, and a consistent downward trend appears most visible during the final yoga phase (B_2) compared to the reversal phase (A_2). The CDC method affirms that systematic change occurred for both level and trend in the direction of the hypotheses.

Variability exists across phases, yet the greatest variability is present during the A phases. When examining days in which Nina practiced yoga during the B phases, there is a clear decrease in variability and range compared to A phases and even compared to days she did not do yoga during the B phases. *Consistency* in patterns of responding can be viewed when examining variability and range across A phases compared to B phases. *Latency* effects consistent with hypotheses are not observed, and likely impacted by the variability.

In conclusion, although no systematic changes in mean and trend are observed from A_1 to B_1 with regard to stiffness intensity, changes are observed through visual inspection from B_1 to A_2 and from A_2 to B_2 . CDC method also supports systematic changes across the majority of these phases. Variability and consistency effects are additionally observed and in alignment with hypotheses. In summary, systematic change in Nina's stiffness intensity is not observed across all phases, yet there is strong support for significant change from B_1 to A_2 to B_2 , in alignment with predicted hypotheses.

Duration of Morning Stiffness. As can be viewed from Figure 7, when comparing *levels* of morning stiffness duration between baseline (A_1) and the first yoga intervention phase (B_1), one can clearly detect a decrease in the level through visual inspection which is also supported by the CDC method. When comparing B_1 with the reversal phase (A_2), changes in level are not visually observed and CDC affirms this conclusion. Lastly, both visual inspection and the CDC method yield a systematic change in level from A_2 to B_2 .

With regard to *trend*, baseline data (A_1) appear to be trending downward yet there is variability within the phase. A more consistent pattern of downward trending can be viewed via visual inspection during the first yoga phase (B_1), compared to baseline (A_1), but not striking enough to draw systematic conclusions between the two phases. The CDC method does in fact indicate a systematic change from A_1 to B_1 (13 out of 13 yoga points are above the trendline), but in the opposing direction of hypotheses. Comparing trends between B_1 and A_2 , visual inspection reveals a difference, which is also supported by the CDC method and aligns with hypotheses. Finally, both visual inspection and the CDC method yield a systematic change in trend from A_2 to B_2 .

A significant decrease in the *variability* of Nina's reported duration of morning stiffness can be visually observed over the course of the intervention (A_1 to B_2) with the final yoga phase (B_2) exhibiting the least variability overall. Additionally, *consistency* in the pattern of data is stronger between B phases than A phases. There are no *latency* effects indicative of immediate patterns of change coinciding with intervention onset.

To summarize Nina's morning stiffness data, not all phase comparisons suggest systematic change via visual inspection or CDC method; however, most yield results consistent with hypotheses. Significant changes in means are present from A_1 to B_1 and A_2 to B_2 ; whereas

significant changes in trend are portrayed from B_1 to A_2 and A_2 to B_2 . Consistency patterns and decreases in variability also support hypotheses. Although Nina does not meet stringent criteria for systematic change across all phases, there is some evidence supporting the hypothesis that the intervention decreased morning stiffness duration.

Three-month follow-up. With regard to Nina's 3-month follow-up, although she did not practice yoga at the same frequency as during the active intervention, she reported consistent practice with the DVD. The level of Nina's pain scores is higher than the B phases, yet lower than A phases. Pain scores appear to be trending downward when she practiced yoga, but as a whole, the two-week phase during follow-up did not exhibit a clear trend. The patterns of consistency and variability were more similar to B phases than A phases, and she did not report a pain score above a 4 on days that she practiced yoga. In terms of Nina's stiffness intensity, scores at 3 months were quite variable and no clear trend is observed. The range of scores at 3 months is most similar to B_2 , but the level and pattern of data are most reflective of A_1 . For duration of stiffness, Nina's scores were variable, thus lacking a clear trend. The overall level appeared most consistent with the baseline phase. With regard to consistency and variability, on days in which Nina did yoga during 3-month follow-up, her scores never exceeded 40 minutes, which is similar to B phases on days in which she practiced yoga. When she did not practice yoga, her scores increased and were comparable to the baseline phase (A_1) and non-yoga days during the B phases. Given the differences in the amount of yoga Nina practiced during the active intervention compared to follow-up, it is difficult to conclude if 3-month data support primary analyses suggesting change due to the intervention. Although she did not appear to maintain gains she made at the end of the intervention (B_2), data suggest she may continue to benefit from yoga on days in which she practices.

Percent Change from Waking to 30 Minutes Post-Waking

Another way to examine changes in pain and stiffness intensity is through percent change scores. Pain and morning stiffness generally decline over time when patients with JIA awaken in the mornings; however, it was hypothesized that the amount of reduction in pain and stiffness from waking to 30 minutes later would be greater during the yoga phases (B₁ and B₂) compared to the baseline and reversal phases (A₁ and A₂). Table 3 describes average reduction in pain and stiffness across phases and percent change scores associated with changes from one phase to the subsequent phase. Such results reflect the immediate impact of the yoga practice on participants' self-reported pain and/or stiffness. On average, both participants pain scores, especially Nina's, demonstrated a larger decrease from waking to 30 minutes later during the weeks they practiced yoga. Additionally, Nina's scores suggested a decrease in stiffness intensity during yoga weeks.

Treatment Effects Associated with Secondary Aims

The secondary aims of this study were to explore the impact of the yoga intervention on psychosocial well-being measured by self-efficacy, mindfulness, and health-related quality of life (HRQOL). Self-efficacy and mindfulness measures both yielded total scores for each of the three time periods: pre-intervention, post-intervention, and 3-month follow-up (FU). HRQOL was also assessed at these three time periods and yielded a composite score as well as four sub-scores: fine motor, gross motor, psychosocial, and systemic. Scores for all psychosocial variables can be found in Table 4. Percent change scores were calculated in order to compare scores in each domain from pre-intervention to post-intervention and post-intervention to FU.

Results of Secondary Aims: Jen

Jen's self-efficacy scores exhibited modest changes. She displayed a 10% increase in self-efficacy from pre- to post-intervention, which is in the direction consistent with hypotheses

and demonstrated a small decrease (4.5%) from post-intervention to FU. Jen's mindfulness score increased 18.6% from pre- to post-intervention, consistent with hypotheses, and decreased 13.7% from post-intervention to FU. Given that she only minimally continued yoga practice following the intervention, her decrease in both self-efficacy and mindfulness scores at FU is consistent with the hypothesis that gains would be maintained contingent upon continuation of regular yoga practice.

Regarding HRQOL, Jen's total composite score improved 27% from pre-intervention to post-intervention and only minimally worsened at FU (5.5%). Her gross motor functioning improved 40% from pre- to post- intervention but she reported decreased functioning (22%) at FU. Fine motor functioning improved 30% from pre- to post- intervention and continued to make small gains (6.7%) at FU. Contrary to hypotheses, Jen's psychosocial score worsened by 12.4% from pre- to post-intervention and then improved slightly (6.7%) from post-intervention to FU. Jen reported improvement on the systemic subscale (31.3%) at post-intervention, and then a decline at FU (9.1%). In summary, Jen demonstrated improvement across all HRQOL scales from pre-intervention to post-intervention except for psychosocial functioning, and results varied from post-intervention to FU.

Results of Secondary Aims: Nina

Nina's self-efficacy scores made a small but steady incline from pre-intervention to post-intervention (6.4%) and from post-intervention to FU (6%). This is consistent with hypotheses as Nina reported twice-weekly engagement in yoga practice following the intervention. Her mindfulness scores were quite stable, contrary to hypotheses, as can be gleaned from Table 3.

Nina's HRQOL composite score worsened from pre- to post-intervention by 11.1%, contrary to hypotheses, and then improved by 8.2% from post-intervention to FU. Gross motor

functioning demonstrated minimal change (3.1%) from pre- to post-intervention and only slightly improved at FU (6.1%). There was no change in Nina's fine motor functioning from pre- to post-intervention, but a 20.7% improvement from post-intervention to FU. Contrary to hypotheses, Nina's psychosocial functioning worsened by 33.3% from pre- to post-intervention, and then only improved 5% from post-intervention to FU. Again, in opposition to hypotheses, Nina's scores on the systemic subscale worsened by 19.6% from pre- to post-intervention and exhibited no change from post-intervention to FU. To summarize, none of Nina's HRQOL scores improved from pre- to post-intervention, yet they either improved or remained the same from post-intervention to FU.

Anecdotal Reports

Jen and Nina were both asked to orally respond to a series of open-ended questions at the end of the last yoga session (end of B₂). Jen cited increased awareness as one of the main aspects of the yoga intervention that was helpful to her. She described that participating in the study helped improved her awareness of her pain, which impacted her ability to control it by using the yoga strategies she had learned. Nina also reported that the yoga practice provided her with a tool to control her arthritis pain. Both stated that they would recommend this type of yoga to others with arthritis. Given the burden of asking participants to practice yoga in the mornings before school, our team was curious to assess participants' perspectives about the utility of morning yoga practice. Both participants reported that morning practice was the best time of day, since that is when their pain and stiffness tended to be the worst; however, both indicated the challenges associated with waking up earlier and completing the yoga practice before school. Neither one suggested that the yoga practice be shortened, but rather, they requested more yoga movements for both the in-person instruction and the DVD.

Participants were also asked to respond to a series of open-ended questions through a questionnaire format at 3-month follow-up. These questions pertained to continuation of yoga practice following the intervention. A complete list of questions can be found in Appendix J. Both participants reported practicing yoga between the end of the intervention and their 3-month follow-up. When given answer choices to select from, Jen indicated that she practiced yoga one time every two weeks; whereas Nina reported that she practiced 1-2 times per week. When assessing the same information in an open-ended format, Jen estimated that she had practiced yoga a total of 10 times since the end of the intervention and Nina reported practicing 20 times in that same time range. Parents were asked to report on the same questions; however, parents indicated not having a sense of when or how frequently participants engaged in the practice both during the study and between post-intervention and follow-up and thus parent responses are not included. With regard to motivation to continue practicing yoga, Jen stated that yoga helped her joint pain in the mornings and Nina cited joint pain and stiffness as reasons for continued practiced.

DISCUSSION

Despite medical advances in the treatment of JIA, pain and stiffness continue to be problems for youth with arthritis, and multidisciplinary approaches are needed to address such concerns (Bromberg et al., 2014; Stinson, Luca, & Jibb, 2012; Tupper et al., 2013). The primary objective of this study was to assess the impact of a yoga intervention on pain and stiffness in adolescent girls with JIA through a single-case design, and secondarily to explore any additional psychosocial benefits of the intervention. It was hypothesized that pain intensity, morning stiffness intensity, and duration of morning stiffness would decrease when participants engaged in the yoga practice instructed through this study and that participants would report improvements in self-efficacy, mindfulness, and health-related quality of life.

Primary Outcomes

Results varied between the two participants and across the three primary outcomes. Jen did not exhibit overall systematic improvement as a result of the yoga intervention. Although Jen's data did not reflect systematized changes in pain intensity, stiffness intensity, or duration of morning stiffness when comparing the weeks Jen engaged in yoga practice to non-yoga weeks, the final two phases of the intervention did reflect trends toward a change in pain intensity. Findings may be related to Jen's poor adherence to the yoga protocol prescribed by the study, as she did not consistently practice the number of prescribed tracks from the yoga DVD, particularly during the first yoga phase of the study. Nonadherence has been found to be related to characteristics of interventions such complexity (e.g., requirement of a lifestyle change) or time/duration of commitment (Lemanek, Kamps, & Chung, 2001; La Greca & Mackey, 2009). Therefore, it is not surprising that Jen had difficulty maintaining adherence given the requirements of the intervention. During the second yoga phase, she slightly increased her yoga

engagement, and results reflected movement toward decreased pain when comparing the reversal phase and last yoga phase. When examining changes in pain from waking to 30 minutes later, Jen reported less pain during yoga phases, and the greatest reduction in pain during the final yoga phase. Thus, the amount and duration of daily yoga practice may have been responsible for the trends in pain reduction that were observed in Jen's data. No significant findings were present for Jen regarding stiffness intensity or stiffness duration.

Results were more favorable for Nina. Findings revealed that the yoga intervention was effective at reducing Nina's morning stiffness intensity and the duration of her morning stiffness; however, not all phase changes were consistent with hypotheses. Despite variability in the baseline data, Nina's results suggested a clear change in stiffness intensity consistent with hypotheses in two out of three phase changes (B_1 to A_2 and A_2 to B_2). Further supporting a change in stiffness intensity, Nina reported a substantial decrease in stiffness from waking up to 30 minutes later during the yoga phases. With regard to stiffness duration, although not all phase changes aligned with level and trend hypotheses, Nina's patterns were reflective of change resulting from the intervention. Again, systematic differences were observed in two out of three phase changes. What is most striking about the impact of the intervention on Nina's stiffness duration is the decrease in the variability of her scores. Comparing yoga and non-yoga phases, a significant decrease in the variability in scores can be seen during the yoga phases; however, it is noteworthy that within the yoga phases on days when Nina did not practice, her duration of morning stiffness rose to levels comparable to those often seen in non-yoga phases. This may suggest that the yoga practice had an immediate impact on decreasing her length of morning stiffness, but when she abstained for one day, the duration of morning stiffness returned to baseline levels. This is consistent with literature suggesting that yoga can have an immediate

impact on functioning, even yoga conducted for a short length of time. For example, a study examining a workplace yoga intervention for adults revealed that participating in fifteen minutes of chair-based yoga postures acutely improved perceived stress via physiological and psychological markers, and benefits were maintained for an additional 15 minutes during a post-intervention period (Melville, Chang, Colagiuri, Marshall, & Cheema, 2012).

With regard to pain intensity, although Nina's data did not align with stringent criteria for systematic change across most phase changes, her scores closely approached the CDC cut-offs and visual inspection provided mild support for changes observed across criteria. In summary, within-phase variability, particularly among Nina's baseline pain scores, limited clearer conclusions from being drawn; however, numerous phase changes closely approached systematic differences. In addition, Nina reported robust reductions in her mean pain level from waking to 30 minutes later during both yoga phases compared to baseline and reversal phases.

Secondary Outcomes

The secondary objectives of this study were to explore the impact of the yoga intervention on psychosocial domains including self-efficacy, mindfulness, and health-related quality of life. Both participants exhibited modest improvements in self-efficacy from pre- to post-intervention. Whereas Nina continued to make small gains at the 3-month follow-up, Jen did not. Anecdotally, Jen stated that one of the ways in which participating in the study helped her was to be "more able to control [arthritis]." Although Jen's single-case data did not reflect systematic changes in pain or stiffness, her perceived control of her arthritis improved from pre- to post-intervention. Nina demonstrated incremental differences in self-efficacy from pre- to post-intervention and from post-intervention to 3-month follow-up. Her continued gains may be associated with continuation of yoga practice following the intervention. The finding that both

Jen and Nina exhibited increased self-efficacy at post-intervention is consistent with literature suggesting that engagement in self-management interventions can improve self-efficacy for persons with arthritis (Smarr et al., 1997).

With regard to mindfulness, Jen's scores were consistent with hypotheses such that she made gains from pre- to post-intervention. Additionally, during focus groups, Jen reported that she noticed an increase in awareness of her body and her surroundings during days and weeks she practiced yoga and described that she believed her self-reported improvements in pain were linked to the heightened awareness she felt through practicing yoga. There was negligible change in Nina's scores from pre- to post-intervention to follow-up. Nina's anecdotal comments indicated that she viewed the intervention as quite physical and pain-focused, and did not describe psychosocial benefits aside from meeting others with JIA. It is possible that the yoga intervention did not include a salient enough mindfulness component to detect greater changes on this outcome measure.

Although mean scores and percent change were calculated for HRQOL, this outcome measure was largely interpreted anecdotally as a way to supplement information about participants' experiences. Jen exhibited improvements in HRQOL across domains assessed from pre- to post-intervention, except for psychosocial functioning. In the psychosocial domain, she reported missing school as one of her most salient complaints, but overall had few psychosocial complaints and scored them quite low. Relative to other domains, her functioning in this area worsened, but overall Jen's HRQOL seemed to improve. Given that Jen's single-case data did not reflect improvements in pain and stiffness, but Jen anecdotally (i.e., both via the JAQQ and focus group discussion) indicated improvement from the intervention, it is likely that her perceived HRQOL improved.

Nina did not report improvements in any domain on the HRQOL scale and cited psychosocial and systemic problems as her highest complaints. Some of the specific concerns that Nina reported included stiffness and limited strength (i.e., systemic subscale) and feeling frustrated and interacting poorly with siblings (i.e., psychosocial subscale). It is possible that her disease activity worsened over time or that Nina may have experienced heightened psychosocial stressors at home or school that were not fully captured by the study questionnaires, contributing to her decreased HRQOL score. Although Nina's single-case data were reflective of improvements in pain and stiffness over the course of the intervention, her self-reports as captured by the JAQQ indicated that she experienced challenges across domains of functioning. It should be noted that, for the JAQQ, comparisons to normative healthy samples were not available, nor were there norms for youth with JIA, further limiting interpretation of the data.

Strengths

During recruitment, there was high interest from patients and their families with regard to joining the study, which was perceived to be a strength. Anecdotally, patients and families were often excited about yoga and disappointed when they did not meet study inclusion criteria. All but one adolescent approached (out of 22) was interested in participating. Also based on anecdotal statements, participants reported a desire for more yoga classes suited to persons with arthritis located close to their homes. Both Nina and Jen reported continued yoga practice three months after the intervention ended. Thus, upon recruitment and for those who completed the study, the treatment may be viewed as a modality with high acceptability. One reason for the this initial acceptability at recruitment may be linked to the growing popularity of yoga in the United States. A yoga-based adjunctive treatment may be perceived by adolescents with JIA as a non-stigmatizing self-care activity in which they are able to participate. Despite high acceptability at

recruitment, logistics of participation compromised the overall acceptability of the treatment, as reflected by the high attrition rates during the course of the study.

Most yoga programs available in the community are not developed for or accommodate individuals with chronic disease, pain, or specific limitations of movement. Furthermore, many yoga programs within the community as well as those described in the literature necessitate props, special equipment, and instruction with a highly trained instructor (Iyengar, 2008).

Although initial learning of the yoga sequence instructed in this study with a trained professional is important, the Joint-Freeing Series™ is safe and gentle enough for youth to engage in independently once they are comfortable with the sequence. Thus, providing a yoga technique that was created to target problems faced by individuals with JIA and adapted to meet their needs was an advantage in terms of intervention specificity.

Although one of the other main strengths of this study was the focus on creating an accessible intervention through the combination of brief in-person intervention and home-based practice with a DVD, the high attrition rate and low adherence to the protocol suggested that the program was still not as highly accessible as desired, and feasibility was subsequently a challenge. Given the demanding schedules and stress levels of teenagers today (Stress in America Survey, 2013), a self-management program that can be conducted in 30 minutes or less was thought to be ideal. However, despite explicit aims to increase feasibility of participation, patients still had difficulty finding the time to engage in the protocol. Aspects of the current program such as using a style of yoga that is simple and safe enough that teens could engage in it independently without weekly or bi-weekly instruction are still considered strengths. The inclusion of a DVD specifically designed for adolescents was developed to support participants' ability to self-manage their JIA symptoms at home, obviating the need to rely on attending a

daily or weekly class. Knowing that adherence to medical regimens in pediatric populations is poor (La Greca & Mackey, 2009), specific steps were taken to improve the accessibility, yet the results and conclusion of the current study suggest undeniable challenges in feasibility. Finally, participants also reported enjoying meeting other youth with JIA, which was a strength of the study fostered by a group format.

Limitations

The most significant limitation of this study was the lack of stable baseline data. Although an important criterion of single-case design methodology is stable baseline data, there are populations with crucial characteristics that vary by nature; yet it continues to remain important to investigate novel interventions with such groups using single-case design methodology. Some authors (Watson and Workman, 1981) suggest that consistency in baseline data for single case designs is so critical that participants who fail to exhibit a stable baseline should be eliminated from analyses. Others (Christ, 2007) caution that data exclusion may “obscure interpretation” and suggest that any systematic exclusions be reported and noted as limitations of the study. Because JIA is characterized by fluctuations in disease activity, including within- and between-day variations in pain and stiffness, gathering stable baseline data may be challenging, particularly for those whose disease is not optimally managed and may be seeking adjunctive treatment. For example, a recent study examined the within-day variability of pain in children and adolescents with JIA and suggested that disease severity was associated with greater pain variability, and that higher pain variability was a predictor of lower quality of life (Tupper et al., 2013). Thus, patients with worse disease severity and greater pain variability likely need more access to adjunctive therapies and research to support such treatments.

Therefore, it is important that this subset of youth not be excluded from research due to the nature of their variable pain report.

Variability in arthritis pain may be attributed to a variety of external and internal factors such as stress, weather conditions, sleep, and activity level (Stone, Broderick, Porter, & Kaell 1997; Strusberg, Mendelberg, Serra, & Strusberg 2002). In the current study, anecdotal reports shed light on some of the individual factors that may have contributed to outcomes such as adherence, pain/stiffness reports, and HRQOL. For example, it was known that Nina was applying to college at the time of her participation, which can be a source of great stress for high school students. Jen was participating in a school play during the time of the study, which may have contributed to her having less time for engagement in yoga. Neither one endorsed changes in medication during the study, and the current study did not capture if or when participants became ill with other conditions (e.g., flu, cold, infection), which may have influenced primary and secondary outcomes.

Another weakness of the current study was exclusively using self-report pain data. Although self-report is the gold standard for pain measurement and is also typically used in rheumatology settings for reports of stiffness, information regarding participants' pain from other informants such as parents or siblings may have revealed nuanced findings not exhibited in self-report data. Next, using only daily self-report data did not allow us to track actual completion times of diaries. Self-report was also relied upon to gather information about whether or not participants engaged in the yoga practice and their duration of daily practice. Although there was no verification of participant practice, adolescents were reminded in each yoga group session of the seriousness and importance of being truthful about their engagement in the practice. Despite efforts to enforce truthful reporting, the lack of verification remains a limitation.

Collecting daily diary data over a long period of time was an additional limitation due to the burden it placed on participants. Further, expectations for participants to practice yoga in the mornings after waking and prior to school, was also burdensome for participants. Participants who dropped out of the study reported that they did not have time in their schedules to engage in the daily yoga practice and/or to attend the weekend groups. Although some participants did not provide further reasoning, others reported that extracurricular activities such as sports (e.g., swim team), required significant time and they could not devote any extra time to the yoga intervention.

Given that pain and stiffness are typically most severe in the morning for girls with JIA (Tupper et al., 2014), the current study involved a morning yoga treatment; however, anecdotal reports from participants revealed concerns about having sufficient time to engage in the yoga treatment before school, and much of the attrition from the study was reportedly due to this concern. Even so, both Jen and Nina suggested maintaining the instructions for morning yoga practice because they perceived that yoga addressed their JIA symptoms of pain and stiffness at a time of day when such symptoms were often at their worst. Other participants whose data were not included reported that they did not have time to practice yoga in the morning and either did it at other times during the day, or engaged in the practice less than was recommended.

With regard to methodology, the major limitation of single-case designs is the lack of generalizability from single cases to the population. Data from the current study suggest that one participant benefited from the intervention, whereas the other did not exhibit systematic intervention effects across outcomes. Although the results from the current study provide an entry into exploration of a specific yoga sequence for this population, methodology and results preclude generalization of findings to a broader population. Additionally, a weakness of the

ABAB design in this study was that the reversal phase may have been influenced by the initial treatment phase. For example, treatment effects for duration of morning stiffness from Nina's first yoga intervention phase may have carried over into the reversal phase. This raises further questions about the immediate impact of yoga versus lasting changes that are maintained days later, which are in need of further study.

The final limitation, which relates to the ecological validity of the study, is that there are few yoga instructors trained in this style of yoga, thus making it difficult for youth with JIA to access classes and programs utilizing the Joint-Freeing SeriesTM. Despite the lack of instructors trained in this sequence, it is a program that any certified yoga instructor may learn and obtain approval to teach, without enrolling in a specific teacher-training course or undergoing extensive training. In sum, this study may increase awareness about the potential effectiveness of a yoga sequence designed to treat JIA-related pain and stiffness and provide encouragement for instructors to incorporate this series into their teaching and hold classes for youths with pain, or more specifically, JIA.

Future Directions

The present study is the first to examine a yoga intervention specifically for adolescent girls with JIA. Additionally, no other studies to date have empirically investigated the impact of this particular style of yoga (i.e., The Joint Freeing SeriesTM). Further assessment of this yoga style as an adjunctive non-pharmacological treatment for pain and stiffness associated with JIA is needed and may warrant exploration in other pediatric pain populations given its gentleness, safety, and simplicity. A factor that is unclear in this study as well as in the broader yoga literature is the amount of yoga that is needed for intervention effects to arise. It is still unknown how frequently a yoga practice must occur and how long the practice must last to produce

physical and psychosocial benefits. Given research suggesting that benefits do not sustain following the termination of yoga classes (Evans et al., 2010), it may be important that researchers find ways to make the yoga programs accessible enough that patients may incorporate them into daily life, thereby improving options for self-management. Additionally, given the numerous demands of adolescents' daily lives, the best time of day to engage in yoga should also be further investigated. For example, anecdotal data from the current study indicated that although it may be more convenient for many patients to practice yoga in the afternoon or evening, more benefit may be garnered if the practice addresses symptoms when they are most salient.

As with any intervention that is done in the home setting, adherence is crucial, as is the accurate report of engagement in the intervention. Future studies that utilize home yoga programs may benefit from the inclusion of a monitoring system to verify participant engagement in yoga. Ideas for future studies may also include parent verification or video/audio recording of participants' yoga sessions on a smart phone. One way to intrinsically motivate participants to continue with the program after study termination may be to show participants their data at the end of the study to provide tangible feedback on their changes in pain or stiffness in relation to yoga engagement.

The use of technology is likely to play an increasingly important role in assessment, adherence, and delivery of interventions for youth with chronic illness broadly (Palermo & Wilson, 2009), and those with JIA specifically (Bromberg et al., 2014; Stinson et al., 2010). For example, using webcam technology and other exercise-based technology adaptations (e.g., Nintendo Wii, Xbox Kinect) may be useful for delivering the intervention and tracking participation as well as engagement in proper technique (Garcia, Felix Navarro, Schoene, Smith,

& Pisan, 2012; Taylor, McCormick, Shawis, Impson, & Griffin 2011). Given that adolescents have reported that the most helpful cue for engaging in physical activity is having a friend to exercise with (Tergerson & King, 2002), and that research has documented that peers and/or friends' social support is associated with increased engagement in physical activity among adolescents (Fitzgerald, Fitzgerald, & Aherne, 2012), future studies may pair adolescents with others. A system such as this may either include having participants engage in yoga simultaneously via webcam technology (e.g., Skype) or have participants use social contact (phone, email, other social media) to confirm and discuss their participation with each other.

Options that may optimize accessibility of the intervention include adaptations to the yoga sequence and DVD based on the fact that pain locations vary across youth with JIA. Further, anecdotal reports from participants in the current study indicated that they wished the DVD had more yoga poses and was longer. Therefore, it may be useful to have a variety of yoga DVDs or sequences to provide a broader array of techniques to choose from. Additionally, the incorporation of more relaxation and mindfulness techniques into the yoga sequence may help participants to obtain greater psychosocial benefits.

With regard to methodology, it may be important and useful to examine other primary outcome measures such as pain interference, pain unpleasantness, functional ability (e.g., participation in activities of daily living), or pain coping. Research in youth with JIA has utilized measures of pain interference and pain unpleasantness for repeated assessments in diary studies, and thus these constructs may be important to consider in addition to pain intensity and duration (Stinson, et al., 2008). In order to gain a better understanding of how yoga may impact youths' activities, it would be useful to collect weekly assessments of functional ability and pain coping.

In conclusion, the current study was a preliminary investigation into the benefits of a yoga intervention on the physical and psychosocial functioning of youth with JIA. Given the desire for adolescents to self-manage symptoms and the aspiration for patients to have access to adjunctive non-pharmacological treatment options, there is a need for more evidence-based multidisciplinary interventions for adolescents with JIA. Future research should continue to investigate acceptable and accessible programs, such as yoga, to empower youth to gain greater control of their symptoms and take a more involved role in their own care.

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Appendix A: Yoga Program and Yoga DVD Script

Yoga Program

The yoga program utilized in this study focused on sequences of movements that were intended to gently and comfortably stretch and strengthen the muscles that support the major joints. It was specifically designed to improve pain and stiffness in the joints as well as enhance psychosocial factors related to well-being. The yoga sequence, called Pawanmuktasana, originally emerged from the Bihar school of Sivananda Yoga in Northeast India and is considered to be an important yoga asana practice that is useful specifically for the management of health disorders (Saraswati, 2008). Although there are three parts to the Pawanmuktasana series, the current intervention only focused on the anti-rheumatic part, as the postures are well-suited to the population at hand. This group of exercises specifically targets arthritis-related pain and stiffness, helps individuals to stretch and strengthen the major joints in the body, assists in relaxing the muscles that surround the joints, and helps to promote body- and self-awareness. Although many of the physical movements may topographically appear analogous to physical therapy movements or exercises, utilization of specific breathing techniques and a focus on cultivating awareness differentiate this yoga practice from the latter.

All asanas in the anti-rheumatic group can be performed in a seated position, which allows for enhanced comfort in persons with arthritis. Physical therapist and yoga teacher, Mukunda Stiles, modified the anti-rheumatic Pawanmuktasana series by including all of the joint groups and provided synchronized breathing techniques to match postures (Stiles, 2000). The modified sequence is referred to as the Joint-Freeing Series™ (JFS) (Stiles, 2000). The series was further modified by shortening the duration by Stiles (personal communication,

2010) and the primary investigator, a certified yoga teacher trained by Stiles, to create a more accessible version for adolescents. See Table 1 for the list of postures included in the sequence.

The study intervention consisted of teaching adolescents breathing (pranayama), the Joint Freeing Series™ with some supplementation from the original Pavanmuktanasana series, and verbal instruction on developing mindfulness, including body awareness and compassion towards oneself and one's body, to help manage pain and stiffness. A yoga DVD was created by the primary investigator to parallel the yoga sequence adolescents were taught during the yoga workshops (see Appendix A). The daily DVD home practice was instructed to last approximately 10-15 minutes. The DVD mirrored the yoga series taught to the adolescents during the groups. The daily practice, however, was instructed to be briefer and more specific to suit the child's individual pain/limitation areas. The full DVD was separated into 6 different tracks that the child was able to choose from based on the most prominent locations of pain; however, all participants were instructed to utilize the second track which consisted of breathing exercises and at least one other track from the DVD that is best suited to their pain regions (ankles/knees/hips; hands/wrists/elbows/ shoulders; back and neck) on a daily basis in the morning before going to school, which would take no longer than 15 minutes total. The practice was instructed to be performed entirely in a seated posture or lying down (floor, chair, or on bed). No standing postures were included in the sequence both to maintain the traditional sequence and also to enhance ease of use, comfort, and safety.

Yoga DVD Script

Track 1

Introduction:

The yoga that we will be doing is based on a sequence called The Joint-Freeing Series™, developed by Mukunda Stiles. We will focus on moving the joints through their full range of motion while using the breath to help us relax. There should not be any stress or straining while doing the yoga postures. If there is pain, the posture should be modified or stopped. Remember that yoga should be comfortable and fun. Also, the movements that you will be learning can be done on the floor, seated in a chair or even in your bed. It is best to practice some yoga for a short period of time every day. I hope that you enjoy learning these gentle movements.

Track 2

We will always begin our yoga practice with breathing. Typically we will be breathing in AND out through the nose. Let's start by taking a moment to notice our own natural breathing and the various sensations in our bodies. What do you notice happening in your body right now?

Three part breath

Let's start by taking a moment to notice our own natural breathing and the various sensations in our bodies. What do you notice happening in your body right now? How about in your mind?...If you begin to have lots of thoughts happening while we are breathing or doing yoga, just see if you can notice the thoughts and then come back to your breathing and the yoga movements.

Now let's place one hand on the chest and one hand on the belly to form what we call a wave breath or the three part breath. Let's start by inhaling a little bit into our chest, a little bit more into the rib cage, and then sending the breath all the way down to the belly filling it with air. Now exhaling releasing from the belly to the ribs to the chest. Again let's breathe a little bit into the chest, then a little more into the rib cage, and then all the way down into the belly. Now we release from the belly to the ribs to the chest.

*Note: In the in-person intervention, participants learn the steps comprising the 3-part-breath. Due to time constriction on the DVD, teaching of the 3-part breath was condensed to what is presented above.

Track 3

Session 1: Ankles, Knees and Hips

In this first group of yoga exercises, we are going to focus on our ankles, knees and hips.

Ankle Extension and Flexion. *Let's begin by extending our legs out in front of us, either holding them out on the floor or the bed, or if you're sitting in a chair extending the legs in front of you, either with your heels off the ground or touching the ground. Begin by pointing your toes and then flexing them. Now let's add the breath. Inhaling pointing our toes, exhaling flexing. Again breathing in pointing our toes, breathing out flexing. See if you can add the wave breath. As you point your toes breathing in from the chest to the ribs to the belly, and exhaling flexing your toes, breathing out, belly ribs and chest.*

Ankle Rotation. *Now are going to do some ankle circles. Start by separating your legs so that they have a little more space. Let's begin by rotating both of our ankles clockwise, breathing in and out as we do this motion. Making very slow and gentle ankle circles. Now let's change direction and make our ankle circles go counterclockwise. As you're doing this see what other sensations you notice in your body. You're probably feeling this in your ankle joints, and maybe even your knees. Do you feel anything in your hips as you're doing these ankle circles? Just begin to notice what other sensations are happening in your body.*

Knee Flexion and Extension. *Now we're going to do a movement that helps to stretch and strengthen the muscles that support our knees. Just like all the other movements this can be done sitting in a chair, on the ground, or in your bed. Let's start by bending the left leg. Take a*

deep full breath with your right leg extended out. Now as you exhale, begin to slide the leg up, bending at the knee. Inhaling again, extending the leg all the way out straight. Breathing out bending again at the knee. Inhaling as the leg extends out, and exhaling as you bring the foot back down to the floor. Now let's switch legs. Bend your right knee, and inhale with your left leg extended. As you exhale, begin to slide the left foot towards your body. Inhaling as you lengthen and straighten your left leg. As you continue with this movement, begin to become more aware of the sensations in your legs. If you're feeling pain at any time just take a break and continue with the wave breath.

Hip Flexion and Extension- Right Leg. Now we will do a movement that helps with range of motion in your hip joint. You can either stand behind your chair, roll over onto one side- on the floor or bed- or come onto your hands and knees. If you are standing behind your chair please use your hands to hold onto the back of a chair. Make sure it is sturdy. For those of you who are lying down, please roll onto your left side and place a something underneath your head. Make sure that you are using your right arm to support yourself by placing your right hand flat on the ground. Let's start with our right leg. Let's all begin by inhaling and extending the right leg back behind you. Now exhaling, bring the knee up towards your head, bending the knee. Breathing in extending the leg back behind you, and breathing out bringing your knee up towards your head. And again inhaling and exhaling. Inhaling and exhaling. Let's do a few more of these.

Hip Flexion and Extension- Left Leg. Now let's switch to the left leg. Let's start by bringing the left leg back behind us as we inhale, Keeping it nice and straight. And exhaling, bending the knee bringing it towards the head. Breathing in extending the leg back behind you, and breathing out bringing your knee up towards your head. And again inhaling and exhaling.

Inhaling and exhaling. As we do two more of these, see if you can notice all of the different sensations occurring in your body.

Hip Adduction and Abduction. *Now let's lie on our backs, and place her feet flat on the ground. Start with your feet about as far apart as your hips. Begin to sway your knees left and right, while your head sways to the opposite side. imagining that your legs are windshield wipers. If you are sitting up in a chair you can move the same muscles by swaying in circles. As you're doing this, breathe in and out of your belly. Now, you can either move your feet wider apart or closer together, it's up to you. Whichever you choose, notice how it feels in your hips and your back. Do you feel more comfortable and relaxed with your feet wider apart or closer together? As you test out the different ways of doing this, it helps you to get to know your body better. It helps you to recognize which movements make your pain better and which don't. Which movement feels best to you?*

As we continue with our yoga practice we will become more aware of our bodies and get to know our bodies better. Knowing our bodies better may help us to better deal with our pain.

Track 4

Session 2: Fingers, Wrists, Elbows, and Shoulders

In the next group of yoga exercises, we are going to focus on our hands, wrists, elbows and shoulders.

Hands- Open and Close. *Let's begin with our hands. Extend your arms out in front of you if that's comfortable for you. If not, just keep your arms by your side. Remember that our yoga exercises should not increase our pain. So make sure to focus on being gentle with your body. Take a deep breath in and at the same time make fists with your hands, but not too tight. As you exhale open your hands releasing any tension. Again breathing in making fists, and then*

releasing the hands. Let's do this together a few more times. Inhaling, exhaling, letting go of stress and tension. Inhaling exhaling, releasing.

Fingers. *Now are going to do a movement specifically for our fingers to help decrease the stiffness. We're going to start by touching our thumbs to the pointer fingers, then our thumbs to our middle finger, and our thumbs to our ring fingers, and finally our thumb to our pinky fingers. Okay let's start over and do this again. Thumbs to the pointer fingers, thumbs to our middle finger, thumbs to our ring fingers, and finally our thumb to our pinky fingers. Let's do it a few of more times. Good.*

Wrists- Flexion and Extension. *Begin by bringing your arms out in front of you. Take a deep breath in pointing your fingertips down towards the floor. As you exhale, allow your fingers to come up pointing up towards the sky. Again inhaling bringing your fingertips down. And exhaling bringing the fingertips up, allowing your palms to show. Let's continue breathing in and out while moving our wrists down and up. One more time breathe in bringing the hands down, exhaling allowing your fingers to point up, showing your palms.*

Elbow-Flexion and Extension. *Now we are going to move on to our elbows. Let's begin with our arms outstretched in front of us. Take a deep full breath in, now as you exhale bring your fingertips up towards your shoulders. See if you can touch your fingertips to your shoulders. If not, just bring them as close as you can. Inhaling again extending the arms out in front, and exhaling bringing the fingertips up towards the shoulders. Again, inhaling extending, and exhaling bending the elbows. Let's do this a few more times. Breathing in, and breathing out. Being gentle with your body, feeling yourself relax.*

Shoulder- Adduction and Abduction. Now let's leave our fingertips on our shoulders, or near our shoulders. Inhaling, begin to bring your elbows behind you, opening up your chest. Now exhaling bringing the arms in front of you, Bringing elbows towards each other. Again breathing in bringing elbows back behind you, feeling your chest getting a nice open stretch. And exhaling, bringing our chin down towards our chest as we bring the elbows towards each other. Let's do this a couple more times. If your mind starts to wander while doing these movements, just bring your attention back to your breathing and the sensations in your body. And one last time, inhaling, and exhaling.

Shoulders- Internal Rotation and External Rotation. The next yoga movement were going to do is also for our shoulders. There are two different ways that you can do this exercise. One way is by bringing your arms down by your sides with your elbows pressing into your waist. The other way is by bringing both arms up making right angles with your elbows. You are free to try both ways to see which you think is more comfortable. Make sure that whichever way you decide feels relaxing for your body. Let's start by inhaling, with the palms facing out. As we exhale, the palms face down, whichever way you're doing the posture. Breathing in, and breathing out. Let's do two more of these.

Track 5

Spine and Neck

In the next group of yoga exercises, we are going to focus on our back and neck.

Spine- Round and Arch. Let's start by doing some stretches that help to loosen up the back. For these next few movements you'll need to sit up either in a chair, at the edge of your bed, or on the floor. Start by bringing your hands back behind you, and placing either your

fingertips, fists, or flat palms on the chair, bed or floor behind you. You can also place your hands in your lap, holding onto your knees. Now as you inhale squeeze your shoulder blades back, open up your chest, and feel your spine gently arching. As you exhale, round your shoulders forward, and bring your chin down to your chest. Again let's inhale squeezing her shoulder blades back, exhaling rounding and bringing the chin to the chest. Let's try to use the wave breath with this movement. Inhaling, chest, ribs, belly, as you arch the spine, exhaling belly, ribs, chest, as you round. Let's do two more of these together. Breathing in, chest, ribs, belly; and breathing out, belly, ribs, chest. One last time.

Spine- Lateral (side to side). *Let's sit up nice and straight. What we are going to be doing here is moving from side to side, but always breathing in to the middle. So let's start by taking a deep breath into the center, and then let's all breath out, going to the right side. As you lean to the right, use your right hand or forearm next to you for support. You can make a fist or have your palm flat on the bed or floor. If you are in a chair, you can actually hold on to the bottom of the chair at the right side. Now let's inhale again to the center, and then exhaling to the left side, using your left hand for support. Breathing into the center again, and then exhaling to the right side; breathing into the center, and exhaling to the left.*

Spine- Twist. *Now we are going to do one last movement for the back. This is a twist. Let's start by taking a deep breath into the center. Now, as you exhale, place your left hand on your left thigh, and bring your right hand back behind you, twisting to the right. Now let's come back to the center as we breathe in. Breathing out, you are going to twist to the left now, keeping your right hand on your right thigh, and bringing your left hand back behind you. And then let's breathe back into the center again. Okay, let's do it all again. Breathe deeply into the center. Now as you exhale, place your left hand on your left thigh, and bring your right hand back*

behind you, twisting to the right. Now let's come back to the center as we breathe in. Breathing out, we are going to twist to the left now, keeping your right hand on your right thigh, and bringing your left hand back behind you. And then we breathe back into the center again. Let's do this one more time. Inhaling to the center, now exhaling twist to the right. Inhaling back to center, and exhaling to the left. Great job.

The next few movements that we are going to do are for our neck. These especially help if you ever get tension in the muscles around your neck. Because these are meant to relax the muscles in our neck, we want to make sure that we are sitting in the most comfortable way possible. You need to sit upright, but you can sit against a wall, chair, or sit any other way that makes you feel most comfortable. Feel free to close your eyes as soon as you get the hang of the movement.

Neck. *Okay, now remember to make sure you are comfortable however you are sitting. Let's start by taking a deep breath as we look straight ahead. Now as we breathe out, gently roll the chin down towards the chest. Then we inhale back up to center. Then exhale, slightly looking up, breathing out through the mouth. Now breathing back into the center. Again gently roll the chin down towards the chest. Then we inhale back up to center. Then exhale, slightly looking up, breathing out through the mouth. Just feel all of the muscles in your neck relaxing. Let's do this one more time. Take a deep breathe into center, then roll the chin down towards the chest. Then inhale back up to center. Exhaling slightly looking up, breathing out through the mouth. Then breathing back into the center. Let's all take a few deep breaths together as we keep our heads facing center.*

Neck- Lateral Inhale to center. *Now, what we are going to be doing is relaxing the muscles on the sides of the neck and also relaxing our jaw. Take a deep breath into the center,*

now exhale through the mouth, relaxing your jaw, bringing your right ear down towards right shoulder. Make sure that your shoulder is not coming up toward your ear, because that could create more tension in the muscles. Remember, we want to relax and be gentle with ourselves. Now inhale back to center. And then exhale bringing left ear down towards left shoulder. Breathing back into center, again let's drop our right ear down towards our right shoulder as we breath out through the mouth, and then breathing into the middle again, now releasing our left ear down towards our left shoulder. Let's do this a couple of more times. Inhaling center, exhaling to the right. Inhaling center, exhaling to the left. And again. Breathing in, and breathing out, breathing in and breathing out.

Neck- Side to side. *The last movement we will be doing for our neck is one where you will be looking out over your shoulder. Feel free to close your eyes, fully letting yourself relax. Let's start by inhaling to the middle. Now as you exhale, turn your head and look out over right shoulder. Inhale back to center. Then exhale, turn head and look out over left shoulder. Inhale back to center, and again exhaling, looking out over your right shoulder, inhaling back to center, and exhaling looking out over your left shoulder. Let's do this a couple of more times. Inhaling center, exhaling right. Inhaling center, exhaling left. And one last time, inhaling center, breathing out to the right, inhaling center, breathing out to the left.*

Track 6

Relaxation

Get into a comfortable resting position, either lying down or sitting upright in a relaxed pose. Allow your breathing to be natural and free. [pause] Letting go of any stress and tension. Feeling all of your joints and muscles relaxing. Now let's take a moment to thank ourselves for

doing something kind for our bodies and minds today. Know that you can carry this feeling of relaxation with you throughout the rest of your day.

Appendix B: Treatment Manual Outline for Yoga Groups

Yoga Session: Group 1

12:00

All participants arrive at 12:00 to complete questionnaire packets. Participants are given 45 minutes to complete the questionnaire packets though it is only expected that it will take up to 30 minutes. The extra time allotted is to account for tardy participants.

12:45

Parents and Teens meet together with team to be given overview of Intervention and Study as well as what will happen today.

- Welcome families.
- All study staff introduce ourselves
- Use ice-breaker for all participants and parents to introduce themselves

Discuss Confidentiality

Ask participants: *Can anyone define confidentiality?*

(Allow participants to respond)

Because many of us will be sharing personal or private information about our health or feelings, it is important that all of the information we share stays in this room. We will not be sharing your information with other people and we would like you all to agree not to share anyone else's personal information with others outside of this group.

Question for participants: *What kinds of techniques have you tried to manage your pain? Do they help? In what situations do they help?*

(Allow participants to respond)

The main skill that you will be learning here to manage pain and stiffness is a gentle and comfortable yoga technique.

Question for participants: *Does anyone know what yoga is? Has anyone ever tried yoga?*

(Allow participants to respond)

Yoga is an ancient practice that originally comes from India which tries to bring the body, mind and spirit into harmony and balance. Many people think of yoga as just physical exercise. And because of magazines and TV, many people think that yoga means you have to twist your body into uncomfortable positions or do headstands. But that's not always the case. And in our groups, that is certainly not the case. We will be focusing on deep breathing, relaxation and comfortable yoga stretches. Because arthritis affects the joints, we will be using movements that specifically move the joints through their range of motion while stretching and strengthening the muscles that support the joints. Everything we do should be comfortable to you and not hurt your

joints. If it does, immediately stop what you are doing and raise your hand. Every yoga movement can be changed or modified so that it does not cause you pain.

Question for participants: *Does anyone know what body awareness is?*

Body awareness means that we are able to identify sensations in our bodies. We know where we feel things and sometimes we even know what they mean. So in the example of the painful knee, body awareness would mean knowing where our knee hurts and knowing that if we sit down, our knee will feel better.

By increasing our awareness of our bodies, we can learn how to identify things going on in our bodies that we may be able to have some control over. In other words, we become smarter about the things we can change. Yoga can help to build body awareness.

Today, the majority of the class will focus on learning this new way to manage pain: gentle yoga. I will be teaching you a technique here today that will take about 45 minutes to an hour to complete the whole sequence. At the end of our time together, we'll be sending you home with a yoga DVD to use every day for just 10-15 minutes. So although we will do a long yoga practice together, you will only be asked to do a short one at home.

While you are in this study, there are some weeks where we are going to be asking you to practice yoga with the DVD every day in the mornings. And other weeks we will ask you to not practice yoga. It is important that you practice every day when you are instructed to because we are trying to understand more about how much or how little yoga kids must do in order to get benefits. For example, if we knew that just 10-15 minutes a day of yoga could make a big difference in kids lives we would want to recommend this to more people. So you are helping us to figure this out so it's really important that you follow the directions.

1:15- Begin Yoga (teens only)

Teens get in a circle of chairs. More detailed introductions include age, grade, how long you have had JIA, what joints it affects the most, what you hope to get out of this group/why you decided to participate. Reiterate the importance of maintaining confidentiality of group members.

Before we begin there are some things that I'd like to tell you about the yoga practice are going to be doing together. Yoga should be comfortable and not painful. Sometimes you may feel a muscle working or stretching which might feel like a slight strain on your body. But you should not be feeling pain, especially not in your joints. As I said before, if you start to feel pain in your joints or anywhere, stop what you're doing and raise your hand. We can adapt to any of the poses so that they are more comfortable. Also we will be focusing on the breath. I'll be teaching you a breathing exercise that is the first track on the DVD. It can be a little confusing at first but you will get the hang of it with practice. During yoga, one of the things that we'll be focusing on are developing more body awareness; specifically, what movements feel good and help the body feel even better, and which movements might be a little bit straining on the muscles the overall help the joints to feel the better.

Our yoga practice will also focus on relaxation. When we are stressed out or in pain it can be very helpful to relax our bodies.

1:15-2:15- Go through the Joint Freeing Series (taking time to explain variations in the postures, make modifications for the kids). ***See Table 1 for details

2:15-2:30 –take a break, small snack provided

2:30-3:00- Group Discussion on how the yoga training went and what to do between now and the next group

Open discussion about today's experience.

Clearly discuss what they are expected to do over the course of the next two weeks:

Over the course of the next two weeks we would like you to practice yoga with the DVD every morning- on school days and on the weekends. There are six tracks on the DVD. The first track is a little introduction that you may want to watch the first time you put the DVD on. The second track is the breathing track. We'd like everybody to do that one before doing the movements on the other tracks. Then you are going to choose what other tracks to do based on where you have the most pain and stiffness. Track 3 focuses on the feet, ankles, knees and hips. Track 4 focuses on hands, wrists, elbows, and shoulders. Track 5 focuses on your back and neck. For example, if most of your stiffness is in your lower body we'd like you to do track 2 and track 3. Track 6 is a relaxation track that you are encouraged to practice at the end of doing the other tracks. We would like for everyone to do at least the breathing track and one other track each day. But it is recommended that you do the breathing track, back and neck, and pick one additional.

Also, you are going to be monitoring your pain and morning stiffness every single day whether you do yoga or not. And we want you to be honest in your answers. It's okay if you didn't do the yoga that day but we really want you to tell us the truth about what you did do and how bad your pain or morning stiffness really is. We know that some days you might not have enough time to do everything we're asking you to do, but we want to know what you did do. Then we're going to ask you to rate your pain when you wake up first thing in the morning, and then again 30 minutes later. We will do the same thing for your stiffness. Then we are going to have you write down how long your morning stiffness lasted. Since you may still be stiff after you leave the house, you can fill that one out when you get back later in the day. Does anyone have any questions?

Give out \$10 Target gift cards.

Yoga Session: Group 2

12:00

Review confidentiality: *Because we may be sharing personal or private information about our health or feelings, it is important that all of the information we share stays in this*

room. We will not be sharing your information with other people and we would like you all to agree not to share anyone else's personal information with others outside of this group.

Parents and Teens together to give overview of Intervention Day 2

12:30- Yoga begins, just teens

Teens get in a circle of chairs. Check-in about how yoga is going. What they need help with, anything hurting? Modifications needed? The major goal of Group 2 is to review the yoga series in its entirety and importantly, to develop an individualized yoga plan for each participant based on the body parts in which they have pain and based on what movements they have benefitting from thus far. This class also includes making modifications of poses for the kids as needed)

Review of some of the important tenets of yoga that we are following:

Remember that Yoga should be comfortable and not painful. Sometimes you may feel a muscle working or stretching which might feel like a slight strain on your body. But you should not be feeling pain, especially not in your joints. As I said last time, if you start to feel pain in your joints or anywhere, stop what you're doing and raise your hand or just speak up. We can adapt to any of the poses so that they are more comfortable. Just like you have been practicing with the DVD, we will be focusing on the breath. Does anyone have any questions about the breathing technique? Today we will be also be talking more about body awareness, specifically, what movements feel good and help the body feel even better, and which movements might be a little bit straining on the muscles but overall help the joints to feel the better.

Today, we'll also talking about acceptance. One of the ways that acceptance is linked to yoga, is that yoga may help us to feel more accepting of our bodies the way that they are. We can learn to have more compassion for ourselves and be more gentle with our bodies. Learning how to feel sensations in our bodies and feel feelings in our minds without judging them, without trying to change them, is an important part of yoga. Just noticing them. Observing thoughts and sensations. Becoming curious about them. As we become more aware, this is an opportunity for us to have more compassion for ourselves and our experience.

12:45-1:45- Go through the Joint Freeing Series yoga sequence— see attachment

2:15-2:30 –small snack provided (fruit, beverages, cookies), discuss today's experience, clearly discuss what participants are expected to do over the course of the next two weeks

Over the course of the next two weeks we would like you to practice yoga every day once again. And just as you did those first two weeks, we would also like you to respond to the surveys everyday to report your pain and stiffness.

Yoga Session Group 3: Yoga review, Focus Group and Discussion

12:00-12:45

All participants arrive at 12:00 to complete questionnaire packets

12:45-1:15

Review participants individualized yoga plans

1:15-2:15 Break, provide snacks for parents and teens

2:00 Parents and Teens

Review of confidentiality: Because many of us will be sharing personal or private information about our health or feelings, it is important that all of the information we share stays in this room. We will not be sharing your information with other people and we would like you all to agree not to share anyone else's personal information with others outside of this group. This will be particularly important today because we will be asking you to share your thoughts and feelings in more detail about your experiences participating in the yoga groups here and about doing the yoga at home. There is no right or wrong response so please make sure to respect everyone else's opinions and feelings.

We also want to remind you that today we will be audio recording our chat session. Your name or any personal information about you will not be used when we present our research. We would just like to learn more from you about how we can better help kids who have arthritis. We are recording this session because it would be very difficult for us to remember all the important things that you say. And because we really value what you have to share, we want to make sure we get all the facts right.

Focus Group Questions:

What did you enjoy most about the yoga classes you attended here at the Emory Children's Center? What was the worst part? What would you change?

What was the best part of being involved in this study? What was your least favorite part about being involved in the study?

Would you recommend this type of yoga to other kids who have arthritis?

What did you enjoy most about the yoga DVD? What was the worst thing about the DVD? What would you change about the DVD? Would you recommend this yoga DVD to other kids who have arthritis?

Did being involved in the study help you in any ways? If so, how?

What did you think about the daily diaries?

With regards to getting up before school? Do you think it would be different if we asked you to do it at night? What do you think is the best time of day?

Thank families for coming. Give out \$10 Target gift cards.
Allow families time to chat and connect with each other.

Alterations to Protocol

Given participants'/families' schedules and number of other commitments, we realize that modifications to the protocol may need to be made. Examples are as follows:

- For participants who are unable to attend the first group session who have already been enrolled in the study and began reporting baseline data, the option to continue with individualized yoga instruction will be made available.
- If all participants who were intended to attend a group become unable to attend, the group will be rescheduled to a time most optimal for the largest amount of participants
- If participants arrive late to the group, modifications in program will be made to accommodate

Table 1

Yoga Postures and Descriptions

<i>English Name of Yoga Posture</i>	<i>Description</i>
<i>Ankles, Knees and Hips</i>	
Ankle dorsiflexion and plantar flexion	Inhale, pointing toes forward; exhale flexing foot back towards self
Ankle rotation	Separate legs, rotate both feet at the same time, moving at the ankle joint; also will feel movement in hip socket. Inhaling as toes move to the right, exhaling toes to the left
Knee flexion and extension	Inhale, extending and straightening leg, activating quadriceps and hamstrings; Exhale, bending knee, bringing heel toward buttocks
Hip flexion and extension	From hands and knees, laying on side, or standing behind chair, inhale extending straight leg back behind; exhale bringing knee up with chin toward chest, rounding the spine
Hip adduction and abduction	Laying on back with feet hip-width apart, sway knees left and right in slow gentle fashion with natural breath
<i>Hands, Wrists, Elbow and Shoulders</i>	
Fingers flexion	Touch each finger to the thumb, one at a time, with both hands. Inhale one round of pointer, middle, ring pinky, and exhale reverse.
Hand clenching and extending	Inhale, making fists; exhale, spreading fingers apart
Wrist flexion and extension	Inhale, pulling fingers up towards sky; exhaling fingers down with palms facing body
Elbow flexion and extension	Inhale arms extended in front of body with palms facing up; exhale bending at elbows bringing fingertips toward shoulders
Shoulder adduction and abduction	Place fingers on respective shoulders with elbow straight ahead at shoulder height. Inhale, open chest bringing elbows behind back towards

	each other; exhale bringing elbows towards each other, touching them in front.
Shoulder internal rotation and external rotation	Bring arms out in front, making right angles with elbows, palms facing out with inhale; exhale swinging forearms down beside waist and rotating the shoulder joint in its socket
<i>Spine and Neck</i>	
Scapula adduction and abduction	Inhale, arching back and squeezing shoulder blades together; exhale rounding spine, tucking chin towards chest, and spreading shoulder blades apart
Spine lateral flexion	Inhale to center, elongating spine; exhale bending directly to the right (or left) side using elbow for support
Spine rotation	Inhale to center with tall spine; exhale placing right hand on right knee or thigh, twisting to the left, turning head and shoulders to the right. Inhale back to center. Exhale placing left hand on left knee, twisting to the right, turning head and shoulders to the left
Neck flexion and extension	Inhale, head up to center. Roll neck down, chin touching chest on exhale. Inhale head back up to center. Exhale slightly looking up breathing out through the mouth.
Neck lateral flexion	Inhale to center. Exhale, bringing right ear down towards right shoulder; inhale back to center. Exhale bringing left ear down towards left shoulder; inhale back to center.
Neck lateral rotation	Inhale to center. Exhale, turn head and look out over right shoulder. Inhale back to center. Exhale, turn head and looked out over left shoulder. Inhale back to center.

Table 2

Means and Standard Deviations of Pain Rating, Stiffness Rating, and Duration of Morning Stiffness across Phases of Intervention and 3-Month Follow-up

	Baseline (A ₁)	Yoga (B ₁)	Reversal (A ₂)	Yoga (B ₂)	3-Month Follow-Up
<i>Participant 1</i>					
<i>(Jen)</i>					
Pain <i>M</i> (SD)	3.4 (2.36)	3.9 (2.13)	4.7 (0.91)	3.5 (0.70)	1.6 (0.82)
Stiffness <i>M</i> (SD)	3.6 (2.79)	3.9 (1.52)	4.4 (1.02)	4.5 (1.29)	2.9 (1.51)
Duration <i>M</i> (SD)	63 (59.65)	56 (17.39)	51 (13.42)	52 (15.54)	52 (16.92)
<i>Participant 2</i>					
<i>(Nina)</i>					
Pain <i>M</i> (SD)	5.5 (2.25)	3.9 (1.29)	5.4 (1.71)	3.3 (1.51)	4.0 (1.52)
Stiffness <i>M</i> (SD)	5.0 (2.23)	4.2 (1.55)	5.1 (1.75)	2.8 (0.98)	4.7 (1.44)
Duration <i>M</i> (SD)	46 (25)	29 (9.17)	30 (7.21)	20 (5)	46 (23.73)

Note: For yoga phases (B₁ and B₂), scores on days that participants did not engage in yoga were removed from calculation

Table 3

Means and Percent Change from Waking to 30-Minutes after Waking*

	Baseline (A ₁)	Yoga (B ₁)	Reversal (A ₂)	Yoga (B ₂)	% Change A ₁ and B ₁	% Change B ₁ and A ₂	% Change A ₂ and B ₂
<i>Participant 1 (Jen)</i>							
Pain <i>M</i> % change	1.64	2.0	1.29	1.82	21.95% +	35.5% -	41.1% +
Stiffness <i>M</i> % change	1.56	2.3	1.36	1.36	47.4% +	40.8% -	0%
<i>Participant 2 (Nina)</i>							
Pain <i>M</i> % change	1.06	3	2.07	3.33	183% +	31% -	61% +
Stiffness <i>M</i> % change	1.5	3.2	2.3	3	113% +	28% -	30% +

**Means based on average difference score within phase. Higher means indicate greater decrease between waking and 30 minutes later.*

Table 4

Mean Scores for Secondary Outcomes at Pre-intervention (Pre), Post-intervention, (Post), and 3-Month Follow-Up (FU)

	<u>Jen</u>			<u>Nina</u>		
Scale	Pre	Post	FU	Pre	Post	FU
Self Efficacy	40	44	42	31	33	35
Mindfulness	43	51	44	49	50	49
HRQOL						
Mean of subscales	4.24	3.08	3.25	4.95	5.5	5.05
Gross Motor	6.0	3.6	4.4	6.4	6.6	6.2
Fine Motor	4.3	3.0	2.8	5.8	5.8	4.6
Psychological	2.67	3.0	2.8	3.0	4.0	3.8
Systemic	4.0	2.75	3.0	4.6	5.6	5.6

Note: For HRQOL, lower scores reflect better functioning.

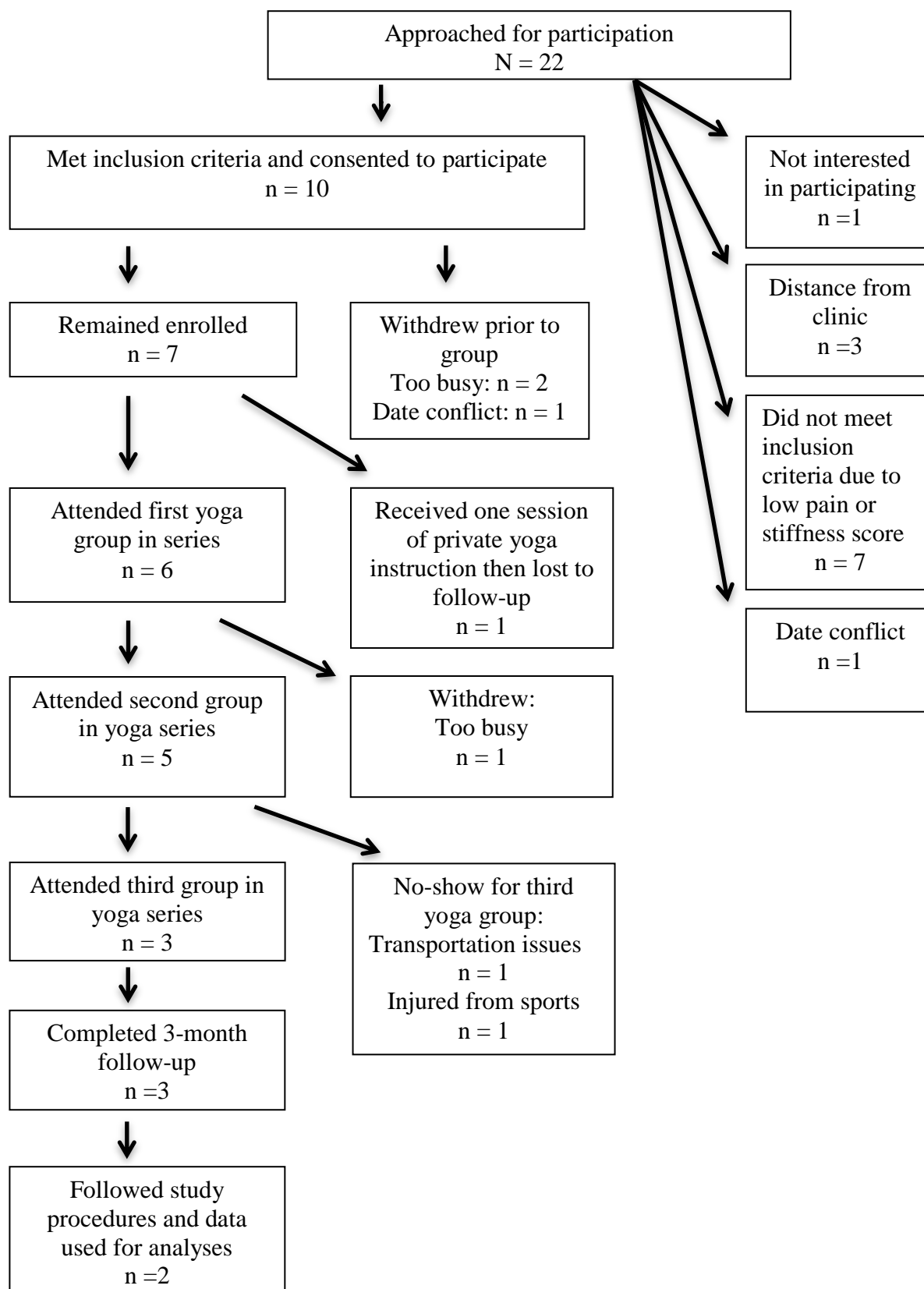


Figure 1. Flow chart of participant enrollment

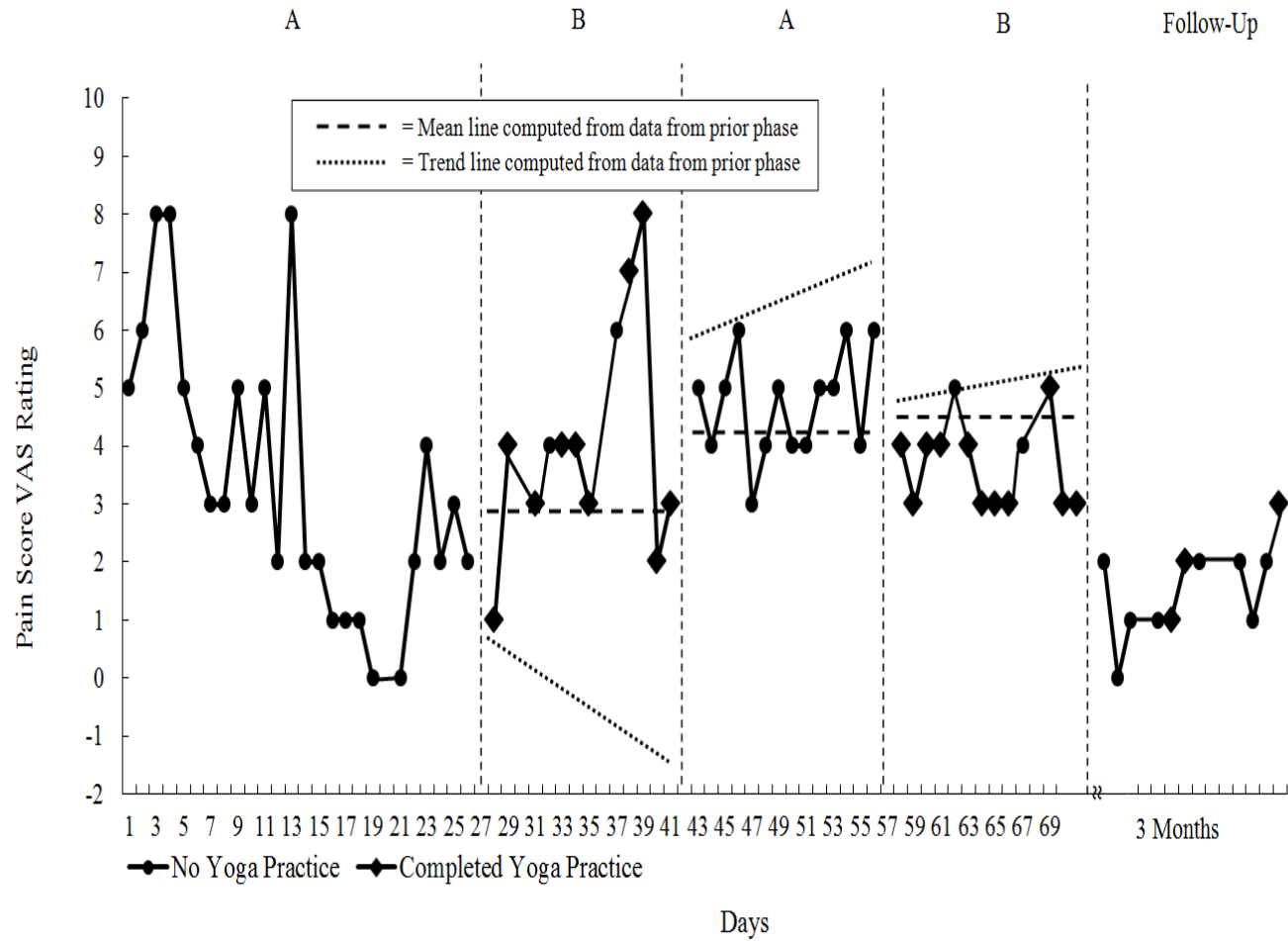


Figure 2. Pain intensity visual analogue scale (VAS) ratings for participant 1 “Jen” during ABAB phases with CDC mean and trend lines and 3-month follow-up

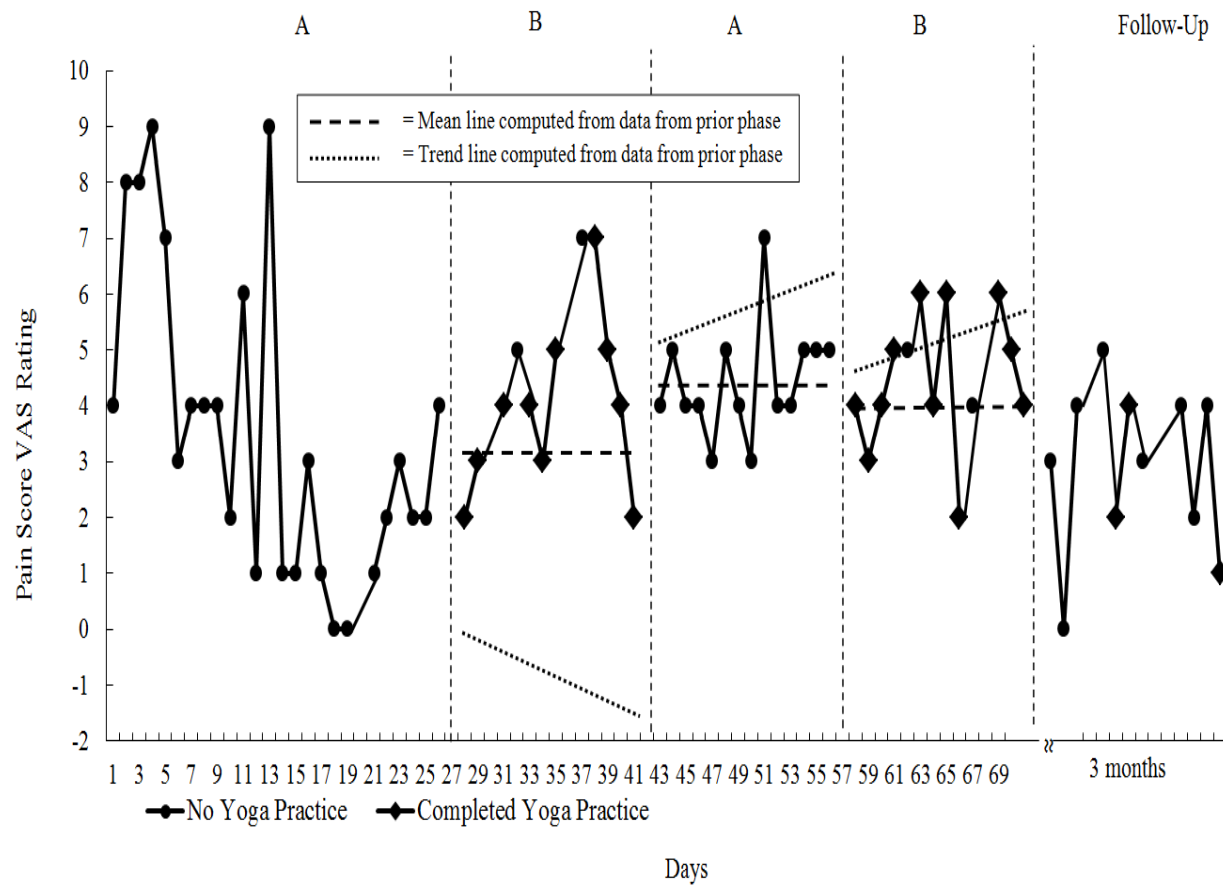


Figure 3. Morning stiffness visual analogue scale (VAS) ratings for participant 1 “Jen” during ABAB phases with CDC mean and trend lines and 3-month follow up

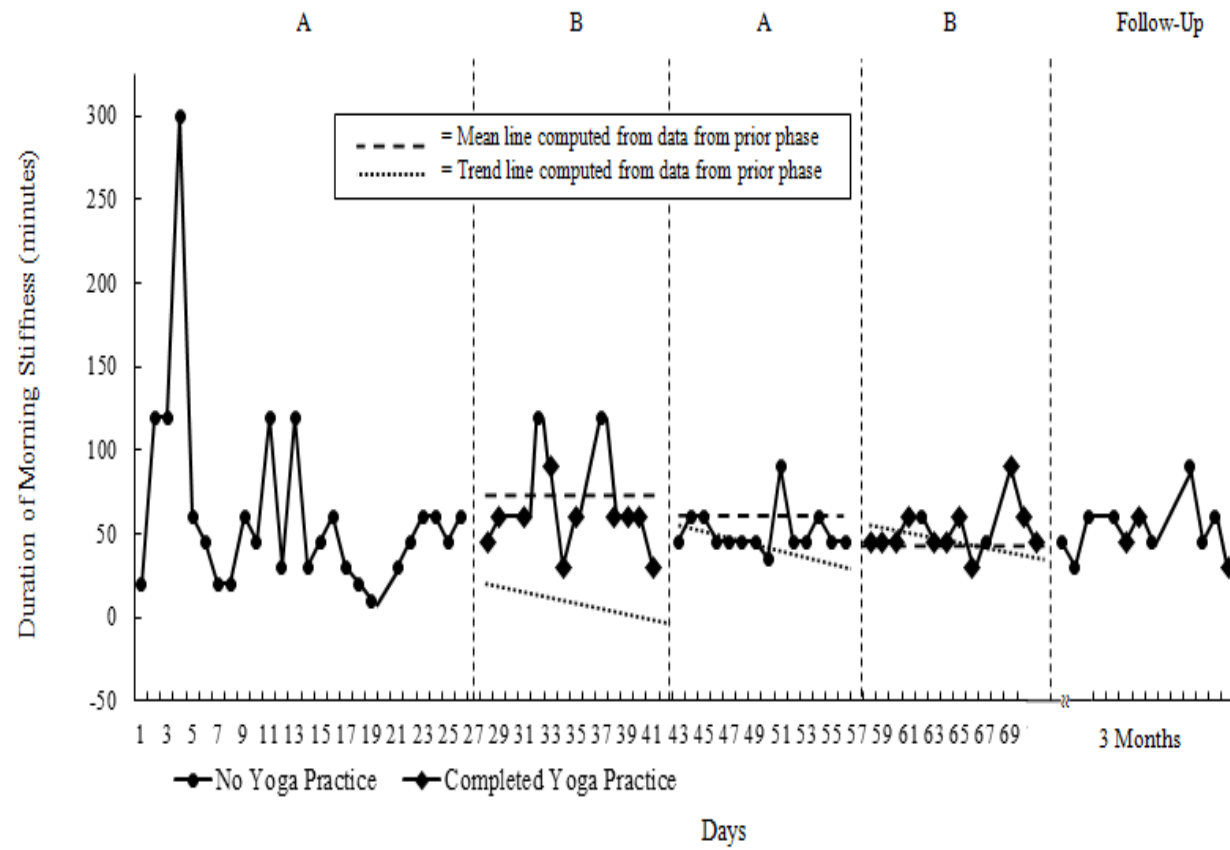


Figure 4. Duration of morning stiffness recorded in minutes for participant 1 “Jen” during ABAB phases with CDC mean and trend lines and 3-month follow up

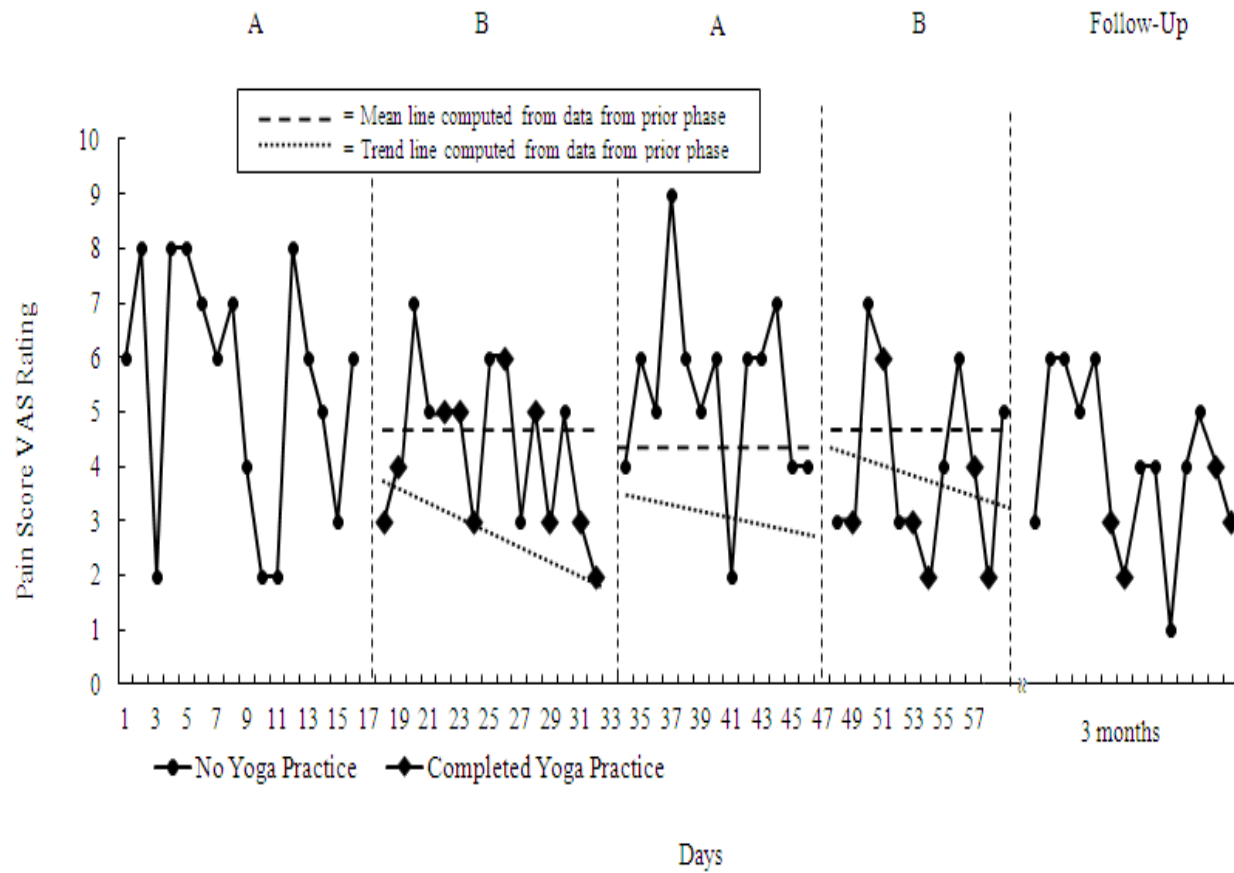


Figure 5. Pain intensity visual analogue scale (VAS) ratings for participant 2 "Nina" during ABAB phases with CDC mean and trend lines and 3-month follow-up

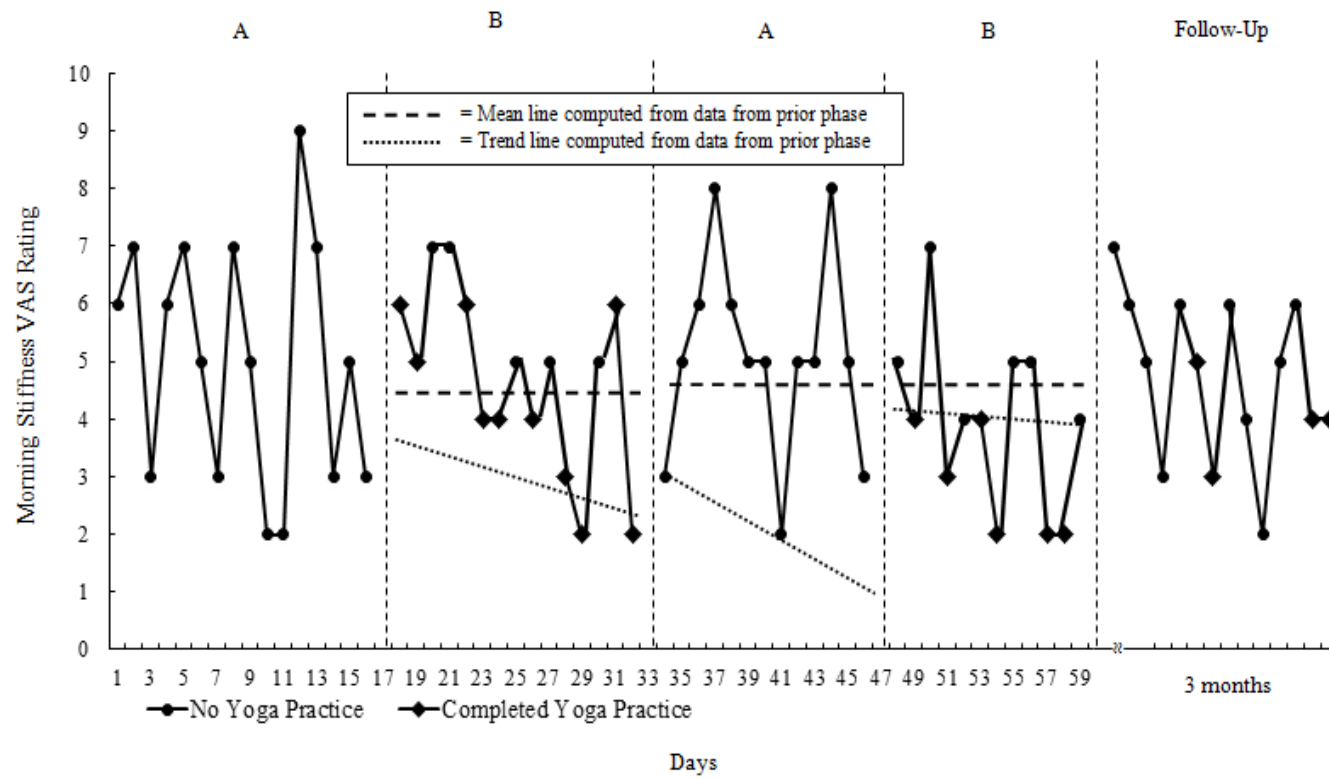


Figure 6. Morning stiffness visual analogue scale (VAS) ratings for participant 2 "Nina" during ABAB phases with CDC mean and trend lines and 3-month follow-up

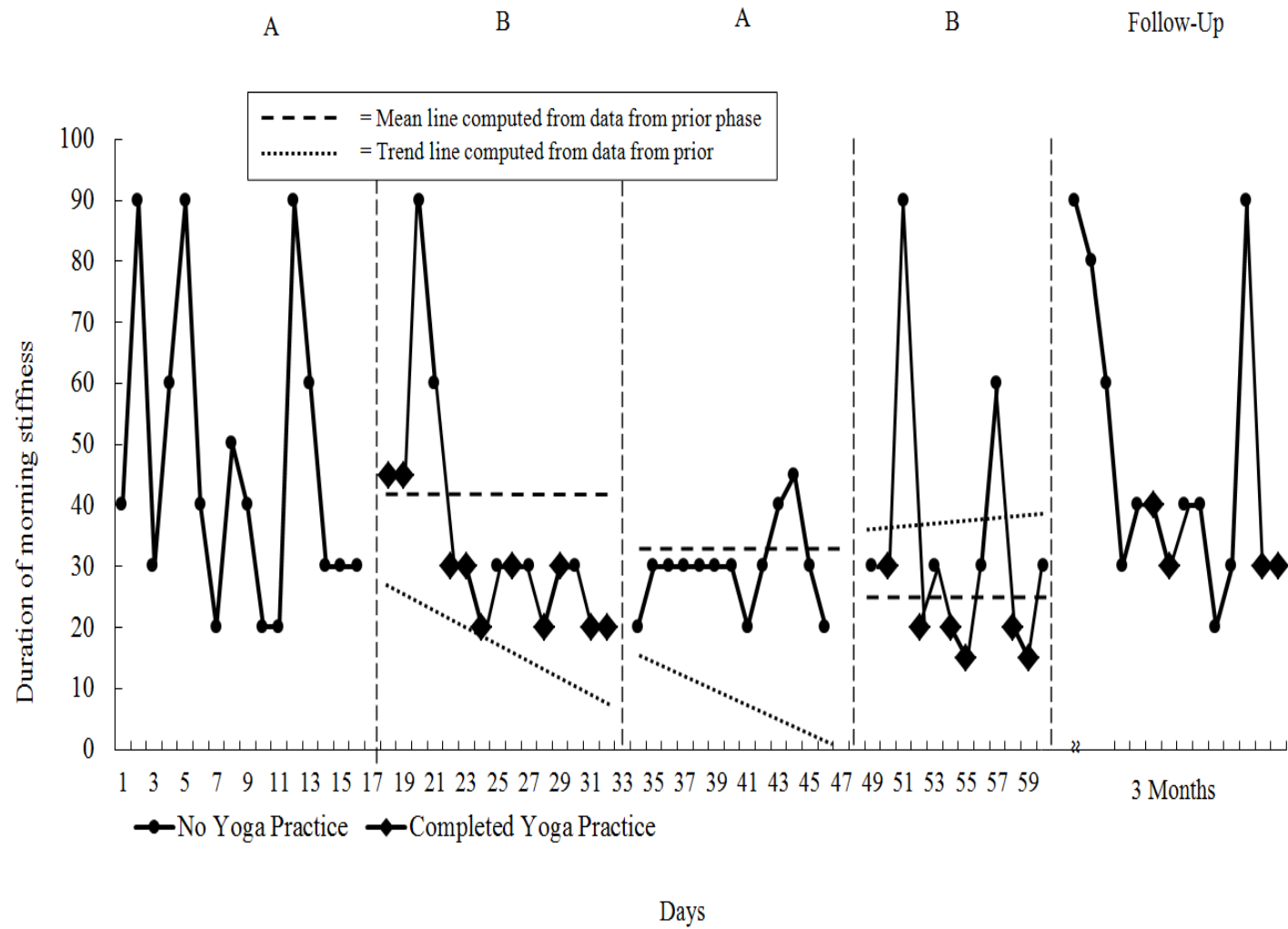


Figure 7. Duration of morning stiffness (in minutes) for participant 2 “Nina” during ABAB phases with CDC mean and trend lines and 3-month follow-up